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ABSTRACT

This abstract bibliography lists approxiately 365 selected resources (published from 1972 through 1990) for promoting the participation of people with developmental and other disabilities in all aspects of community life. The bibliography concentrates more heavily on books, monographs, and unpublished and publicly available documents than on journal articles. It promotes a "support" rather than a "program" paradigm. The six sections of the bibliography deal with the following topics: (1) perspectives on community integration; (2) administrative issues (planning and coordination, funding, and promoting quality); (3) planning with individuals; (4) services and supports for integration (community living for children, community living for adults, education in the regular classroom, integrated employment, recreation and leisure opportunities, supporting people with challenging behaviors and supporting people with complex physical and health needs; (5) resources other than services and supports (self-determination, advocacy, families, acceptance and relationships, and community care); and (6) women with disabilities (general issues, education, employment, and rehabilitation, health, motherhood, and reproductive rights, sexuality and sexual abuse). The bibliography concludes with information on how to order the resources listed and provides indexes by author, title, and subject. (JDD)

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Center on Human Policy

ANNOTATED BIBLIOGRAPHY ON COMMUNITY INTEGRATION REVISED

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ANNOTATED BIBLIOGRAPHY

ON

COMMUNITY INTEGRATION

REVISED

ANNOTATED BIBLIOGRAPHY ON COMMUNITY INTEGRATION

REVISED

Edited
by
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INTRODUCTION

This Annotated Bibliography on Community Integration, Revised lists many of the best available resources on community integration for people with developmental and other disabilities. It is meant to be a resource for people with disabilities, parents and family members, advocates and friends, direct service providers, administrators, and policy makers who are interested in promoting the participation of people with disabilities, especially those with mental retardation, medical and physical involvements, challenging behaviors, and multiple disabilities, in all aspects of community life. It presents resources applicable to many disability groups and represents an extensive revision and updating of the Annotated Bibliography on Community Integration prepared by the Center on Human Policy's Community Integration Project in 1987.

Selection Process

Materials for both editions were initially identified by computerized searches of the ERIC (Educational Resource Information Center), NIMH (National Institute for Mental Health), and MEDLARS (Medical Literature Analysis and Retrieval System) databases and a review of a) bibliographies published by the American Association on Mental Retardation, ERIC, NARIC (National Rehabilitation Information Center), the Beach Center, and other centers engaged in work in the area of community integration; b) the contents of major journals in the field; c) publication lists of major publishers and research centers; and d) the nominations of the staff and associates of the Research and Training Center on Community Integration. Materials culled from this first step were then individually reviewed for inclusion based on the criteria outlined below.

Selection Criteria

The materials identified for this bibliography clearly focus on social integration for people with severe disabilities. We evaluated each resource for the degree to which it reflected the principles of the Center on Human Policy's Research and Training Center on Community Integration:

1) All people with developmental disabilities, including those with the most severe disabilities, belong in the community.

2) Agencies and programs should provide the services and supports people with developmental disabilities need to participate in typical neighborhoods, work settings, and community environments.

3) Agencies and programs should support children to live with families and adults to live in typical homes in the community.

4) Agencies and programs should foster the development of relationships between people with developmental disabilities and other community members.

5) Programs and services provided to people with developmental disabilities should be non-aversive, oriented toward the development of practical life skills, and respectful of personal choices.

6) Parents and people with disabilities themselves should be involved in the design, operation, and monitoring of services.

For this revision, we concentrated more heavily on books, monographs, and unpublished but publicly available documents than on journal articles. For the most part, we eliminated materials that reflected a facility-based point of view, even those that use language implying a community integration philosophy. We identified many materials that promote a "support" rather than a "program" paradigm; that is, they discuss ways of supporting individuals to express and carry out their own choices and preferences for where and with whom they will work, learn, play, and live. We feel that the materials included here reflect a coherent vision of the opportunities people with severe disabilities should have today. We also want to note that the field continues to change, as do the visions of people with disabilities and their families. We hope that some of the resources included here reflect the visions of tomorrow.

The Organization of This Bibliography

Much of this bibliography is divided into sections that reflect different areas in the lives of people with disabilities. We hope that readers will realize that no person's life can be divided neatly into domains, and that no section of this bibliography can stand alone. For example, a reader interested in people with challenging behavior should look at that section but only in the context of other sections, such as "Planning with Individuals," "Community Living for Adults," "Acceptance, Relationships, and Community," "Self-Advocacy," and so on.

Within each section, the materials are organized alphabetically by author. There are three indices in the back to assist readers to find materials by author, by title, and by topic.

Acknowledgements

The editor would like to thank all of the contributors to this edition, and extend appreciation to Pat Rogan, Alison Ford, Carol Berrigan, and Amy Good for their input and assistance in identifying excellent materials for inclusion. Special thanks go to Rachael Zubal for putting the document together, for organizing all the pieces into a workable whole. Appreciation is also extended to James Knoll, who edited the first edition in 1987.

This manuscript was prepared with support from the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), awarded to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University under Cooperative Agreement No. H133B00003-90 and Contract No. G0085C03503. The opinions expressed herein are those solely of the authors and do not necessarily reflect the position or the policy of the U.S. Department of Education and no official endorsement should be inferred.

PERSPECTIVES ON COMMUNITY INTEGRATION

The materials reviewed in this section are intended to give the reader an overview of the historical and ideological perspectives which inform the community integration movement. For that reason, some of these materials may now seem outdated or overly broad, while others are very current. They are presented here because the complex nature of the forces encountered by people with disabilities, parents, and practitioners require a good understanding of the basis for community services and supports and a strong commitment to the principle that the community should include everyone. For more on the perspectives of people with disabilities and family members, please see the "self-advocacy" and "families" sections of this bibliography.

. . . . . .

TITLE: The community imperative revisited

AUTHOR: Biklen, D., & Knoll, J.

PUBLICATION INFORMATION: 1987

In J. A. Mulick & R. F. Antonak (Eds.), Transitions in mental retardation, Vol. III: The community imperative re-examined (pp. 1-27). Norwood, NJ: Ablex.

In 1979, the Center on Human Policy issued The Community Imperative Declaration, which asserts that "All people, regardless of the severity of their disabilities, are entitled to community living." This statement and an accompanying paper became a rallying point for people everywhere who believed in community living for all. This chapter "revisits" the statement and its aftermath, systematically refuting eight major arguments which oppose this position and citing the experiences of a number of formerly institutionalized people. The chapter provides a comprehensive review of the literature on this topic and highlights a number of obstacles which continue to hinder realization of the Community Imperative's goal.

. . . . . .

TITLE: The family papers: A return to purgatory

AUTHOR: Blatt, B., Ozolins, A., & McNally, J.

PUBLICATION INFORMATION: 1979

New York: Longman

This valuable resource is currently out-of-print. It should be available at any library with a solid collection in the area of special education.

A slide show based on the book. The Family Album, is available through the Human Policy Press, P.O. Box 127, University Station, Syracuse, NY 13210 for $55.00 plus $2.50 shipping and handling.

In 1966, Burton Blatt and Fred Kaplan, the former a respected professional in the field of mental retardation and the latter a photographer, shocked America's conscience with the publication of Christmas in Purgatory, a photographic expose of conditions in institutions for people with mental retardation. Ten years later, Blatt, this time with Andrejs Ozolins and Joe McNally, returned to these institutions to document the changes and reforms that had occurred since the earlier expose. The findings are contained in The Family Papers. Filled with photographs of institutions and alternative settings, this book at once documents improved conditions at institutions and captures the more subtle forms of dehumanization which occur there today. As the authors conclude, "As you will see, everything has changed during the last decade. As you will see, nothing has changed." The book presents a compelling argument in favor of community living. Policymakers, parents, and professionals new to the field will find this book especially informative.

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TITLE: Criterion of ultimate functioning and public school services for the severely handicapped student

AUTHOR: Brown, L., Nietupski, J., & Hamre-Nietupski, S.

PUBLICATION INFORMATION: 1976

In M. A. Thomas (Ed.), Hey, don't forget about me: Education's investment in the severely, profoundly, and multiply handicapped (pp. 2-15). Reston, VA: Council for Exceptional Children.

This valuable resource is currently out-of-print. It should be available at any library with a solid collection in the area of special education.

The case is made in this article that programs for individuals with severe disabilities have been oriented towards preparing these people to function in segregated environments. The authors propose a redirection of practice in services to severely handicapped persons toward what they call the Criterion of Ultimate Functioning--"the ever changing, expanding, localized, and personalized cluster of factors that each person must possess in order to function as productively and independently as possible in socially, vocationally, and domestically integrated adult community environments." Some of the factors suggested to facilitate this orientation are 1) integration into heterogeneous community environments; 2) a system of services for persons with severe disabilities which are longitudinal, comprehensive, and coordinated; and 3) the use of instructional approaches that are specifically geared toward teaching needed skills in natural environments.

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TITLE: Living and learning in the least restrictive environment

AUTHOR: Bruininks, R. H., & Lakin, K. C. (Eds.)

PUBLICATION INFORMATION: 1985

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

Recently, the literature has reflected a growing recognition that deinstitutionalization and its complement community integration raises a complex web of issues about disabilities, society's tolerance for difference, the nature of large scale social change and resistance to it, and many others. Throughout this book the various authors concur with one another that any difficulties which attend deinstitutionalization relate to methods of achieving community integration and not to the legitimacy of the goal itself. The authors address an extraordinary range of critical issues with uncommon care and detail. The book provides indepth and far-reaching examination of both the principal, complex barriers to integration and many of the current responses to them.

As the editors note, progress toward community integration has occurred slowly. There may be myriad explanations for the slowness and questionable quality of deinstitutionalization, a policy that has prevailed for more than two decades. This volume examines many of these. This book should be of great interest to all who want to explore the nature of community integration.

TITLE: Site visit reports

AUTHOR: Center on Human Policy

PUBLICATION INFORMATION: 1985-1990

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: Varies by report; ranging from $1.25 to $3.25

Beginning in 1985, the Center on Human Policy's Research and Training Center on Community Integration conducted visits to agencies nominated as demonstrating promising practices in community integration. This series of reports includes views of agencies engaged in supporting adults to live in the community, family support, citizen advocacy, employment, intgrated recreation and leisure opportunities, and other ways of supporting people with severe disabilities. To obtain

a listing and description of each report (a number of which are annotated in other sections), write to the address above.

NOTE: Paul H. Brookes Publishing Co. will publish a book based on these case studies in Summer, 1991, entitled Life in the community: Case studies of organizations supporting people with disabilities in the community.

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TITLE: Normalization, social integration, and community services

AUTHOR: Flynn, R. J., & Nitsch, K. E. (Eds.)

PUBLICATION INFORMATION: 1980

Pro ED
5341 Industrial Oak Boulevard
Austin, TX 78735

This is an edited book that provides a comprehensive review of the principle of normalization. The book is divided into three parts. Part I, "The Normalization Principle: Systematic Statements and Clarifications," includes articles authored by Wolf Wolfensberger, Bengt Nirje, and Neils E. Bank-Mikkelsen which provide an update on the meaning of normalization and address common misconceptions of the principle. Part II, "The Normalization Principle: Implications for Legislating, Implementing, and Evaluating Community Services," contains ten separate articles which deal with legal issues (especially, the implications of the Pennhurst case), special education (a classic article on least restrictive educational environments written by Lou Brown and others), early childhood education, the research on community residential settings, vocational service, regional planning for "communitization," a "supermarket of services" for elderly adults, and program evaluation based on normalization. Part III of the book contains a conclusion by the editors and a comprehensive bibliography of normalization references. Policymakers, planners, and administrators will most find this book useful.

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TITLE: Challenges of emerging leadership: Community based independent living programs and the disability rights movement

AUTHOR: Funk, R.

PUBLICATION INFORMATION: 1984

The Institute for Educational Leadership
1001 Connecticut Avenue, N.W.
Suite 310
Washington, DC 20036

This document reports on the status of the independent living movement. It begins by outlining and discussing the basic principles of independent living which

include: 1) People with disabilities design and run their own programs, 2) These programs are community based and community responsive, and 3) These programs provide services and also undertake advocacy for change in the larger community. The history of independent living and the disability rights movement are recounted. Special emphasis is given to making clear that independent living should not be viewed as just another traditional model of services in a new wrapper. Five major operational issues which confront this movement are discussed along with some recommendations for dealing with them.

Of particular value in this paper are the basic principles and perspectives which the independent living movement conveys. These principles, the section on crucial issues, and the recommendations for the future should be read with an eye to their applicability to all people with disabilities and not just as they apply to those individuals who have traditionally been identified as "candidates" for independent living.

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TITLE: Supported community life and mediating structures: Joining theory to practice in disability policy reform

AUTHOR: Hibbard, M., Ferguson, P., Leined, J., & Schaff, S.

PUBLICATION INFORMATION: 1989

In P. Ferguson & D. Olson (Eds.), Supported community life: Community policy to practice in disability research. Portland: Specialized Training Program, University of Oregon.

This excellent essay explores basic contradictions in traditional social welfare policy, such as its basis in a belief in individual rights and entitlements as opposed to the large-scale institutions and systems that are developed to carry out social policy, and the loss of community and structures that might mediate the influence of "megastructures" on individual lives. It goes on to point out that while these contradictions have also shaped disability policy, the past few years have seen a new concept in disability policy, that of "supported community life," that can be explicated so as to be seen as a mediating structure. The authors point out that "What is new in the notion of Supported Community Life is the guiding commitment to participation and affiliation rather than control and remediation." The essay goes on to discuss services relevant to several life domains that are now framed as supports (supported employment, supported living, etc.) rather than just as programs or services. Finally, it illustrates the ideas being proposed by focusing in on family support services that illustrate the concept of support and that place control with the family, examining the supportive qualities of several programs. This chapter is worth reading for its excellent syntheses of trends in disability policy.

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TITLE: Changing patterns in residential services for the mentally retarded

AUTHOR: Kugel, R. B., & Wolfensberger, W. (Eds.)

PUBLICATION INFORMATION: 1979

President's Committee on Mental Retardation
U.S. Department of Health and Human Services
Office of Human Development Services
Washington, DC 20201

Originally published in 1969, it now includes some new and some revised chapters.

This report, published by the President's Committee on Mental Retardation, is perhaps the single most influential document in the change from segregation and isolation toward normalization and community integration of people with disabilities. The report outlines the status of residential facilities in the late 1960s and describes them "... as a disgrace to the nation" (p. 1), and delineates alternative ways to providing services. The contributors to this volume include several outstanding U.S. leaders in the field of mental retardation such as Burton Blatt, Gunnar Dybwad, Robert Kugel, Seymour Sarason, and Wolf Wolfensberger, as well as a number of European leaders, among them N.E. Bank-Mikkelsen (Denmark), Karl Grunewald (Sweden), Bengt Nirje (Sweden), David Norris (England), and Jack Tizard (England).

The report represented more than just another condemnation of the status of institutional programs in the U.S. in the 1960s. It also provided a thorough examination of the present service system, outlined new ways of providing services, and courses for action. Maybe most importantly, it was this report that brought the normalization principle to the nation's attention in a chapter written by Bengt Nirje where he outlines the theoretical construct of normalization which already at that time underlined much of the Scandinavian legal and service structure in mental retardation. The editors of the volume note that they "...view the normalization principle as perhaps the single most important concept that has emerged in this compendium" (p. 10). Although many of the ideas presented in this report are outdated by now, this historical and classic document was the turning point in the history of services for people with disabilities in the U.S.

TITLE: Beyond Oz: The path to regeneration

AUTHOR: Lehman, K.

PUBLICATION INFORMATION: 1988

Social Policy, Spring 1988, 56-58.

This short article discusses community regeneration, describing characteristics of regenerating communities and pointing out the limits of social policy. Two examples, one of an inner city housing project whose residents took charge and created a flourishing community, and one of a small town in Iowa whose residents began to build on their strengths and commitments to each other, are described. While no mention of developmental disabilities is made in the article, the concept of community regeneration is increasingly of interest in the field today. How can we promote integration when the community itself is disconnected, dispirited, and seemingly absent? This article emphasizes the possibilities in people, the strength of social consensus over social policy.

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TITLE: Ethnic families in America (Third edition)

AUTHOR: Mindel, C. H., Habenstein, R. W., & Wright, R., Jr. (Eds.)

PUBLICATION INFORMATION: 1988

Elsevier Science Publishing Co., Inc.
52 Vanderbilt Avenue
New York, NY 10017

The growing interest in ensuring that services are responsive to the culturally and ethnically diverse groups that make up most communities has produced books and articles that attempt to increase understanding. The most difficult issue such attempts face is that of avoiding further stereotyping of specific groups. This book contains chapters on European (Polish American, Catholic Irish American, Greek American, Italian American), Hispanic (Mexican American. Cuban American, Puerto Rican American), Asian (Korean American, Chinese American, Japanese American, Vietnamese American), historically subjugated (Black American, Native American), and socioreligious (Amish, Jewish American, Arab American, and Mormon) "ethnic" minority families. A good reference source, this book sometimes falls into the trap of perpetuating stereotypes but at other times offers valuable information. For information on any one minority group, this book should be read along with other references (given at end of each chapter) rather than as a sole information source. For insights on the importance of recognizing and affirming diversity, the book provides a valuable overview.

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TITLE: What can we count on to make and keep people safe? Perspectives on creating effective safeguards for people with developmental disabilities.

AUTHOR: O'Brien, J., O'Brien, C. L., & Schwartz, D. B. (Eds.)

PUBLICATION INFORMATION: 1990

Decatur, GA: Responsive Systems Associates.

Available through:
Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $2.20 plus 10% shipping and handling

This excellent and readable monograph is a report on a discussion between participants in a 1989 annual retreat of the Pennsylvania Developmental Disabilities Planning Council. It includes summaries of parts of the discussion and selections from background papers used by participants, and deals with questions that encompass, but are much broader than quality assurance. The editors see the question in the title as one that "frames an important perspective on the continuing work of building communities that offer people with developmental disabilities full and dignified lives." The paper recognizes the vulnerability of people who need longterm assistance to realize their citizenship and community membership, and deals with the insufficiency of currently favored mechanisms for ensuring safety. The discussion looks at various types of advocacy, at lifesharing and other personal commitments, and at support for what families, friends, and service workers do. It also discusses strategies and options for action to increase people's safety.

TITLE: Surviving in the system: Mental retardation and the retarding environment

AUTHOR: People First of California

PUBLICATION INFORMATION: 1984

Capitol People First
6835 Wavecrest Way
Sacramento, CA 95831

This document was produced by People First of California, a state-wide self-advocacy organization, under contract with the California State Council on Developmental Disabilities. The document describes the methodology and results of a needs assessment based on consumer-to-consumer interviews, describes a model for individuals with disabilities to use in their efforts to organize self-advocacy groups or to become better self-advocates, and includes very specific recommendations to public and private agencies and policy making bodies in California on how change can best be effected.

The central theme throughout the document is one of self-advocacy and overcoming the "retarding environment." The authors stress the point that the current service system often does little to promote self-growth and independence, and often discourages and impedes independence.

This book offers a great deal to a wide variety of readers. It obviously is a great value to consumers and their families. It is also an important document to be read by professionals, policy makers and students of human services.

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TITLE: Mental retardation: The leading edge, services that work

AUTHOR: Perske, R.

PUBLICATION INFORMATION: 1979

The President's Committee on Mental Retardation
Superintendent of Documents
U.S. Government Printing Office
Washington, DC 20402

DHEW Publication No. (OHDS) 79-21018

The book highlights 30 effective service programs for mentally retarded persons and is important for historical reasons. The programs represented here demonstrated what was possible at a time when doubt about community integration was still strong. The first section presents information on eight family oriented programs serving high risk, Down's syndrome, urban poor, and profoundly handicapped children. Included are descriptions of parent education, support, and advocacy programs. Among seven public school education programs summarized include a preschool program in which normal children are integrated, a merger between a special school and a regular one, a community centered program for hearing impaired retarded teenagers, and continuing education courses on college campuses. Among the five community residence programs represented are the Eastern Nebraska Community Office of Retardation, the Macomb-Oakland Regional Center (Michigan), and the Tuolumne County Independent Living Project (a rural California program). Three descriptions of effective vocational programs are followed by descriptions of two self-advocacy organizations. Two programs serving mentally retarded offenders and two serving people with mental illness and mental retardation are reviewed. Final sections touch on prevention and future issues (including consumer advocacy systems, special-regular teacher relationships and local community responsibility).

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TITLE: The Willowbrook wars: A decade of struggle for social justice

AUTHOR: Rothman, D. J., & Rothman, S. M.

PUBLICATION INFORMATION: 1984

Harper and Row
10 East 53rd Street
New York, NY 10022

This book traces the history of reforms and litigation at the infamous Willowbrook State School in Staten Island, New York from 1972 to 1983. While the book focuses on the specific experience at Willowbrook, it has general relevance to the issues of institutional reform, the impact of courts on service systems, parent involvement, deinstitutionalization, and community-based services for people with severe disabilities.

Practically everyone interested in people with severe developmental disabilities will find The Willowbrook Wars interesting and useful. Parents will identify with the heart-wrenching experiences and dilemmas of parents of people at Willowbrook. Policy makers and planners will find important lessons about the complexity of reform, systems change, and developing community services. Attorneys and advocates will gain additional insight into the impact of their activities. Service providers will learn about approaches for gaining community acceptance, designing humane and effective programs, planning strategies, the importance of independent monitoring, and current controversies over issues like the size of community living arrangements and community fears of "Hepatitis B carriers." Written in clear language and an engaging style, The Willowbrook Wars is "must" reading for people interested in the community integration movement. Though this book is out-of-print, it should be available at university and municipal libraries or through interlibrary loan services.

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TITLE: Crisis in the community

AUTHOR: Smull, M. W.

PUBLICATION INFORMATION: 1989

National Association of State Mental Retardation Program
Directors, Inc. (NASMRPD)
113 Oronoco Street
Alexandria, Virginia 22314

In this paper, Smull provides strong evidence that community services are in crisis--that understaffing and underfinancing, combined with rigid and inefficient models of service, are having an increasingly adverse effect on quality of care. He proposes a reconceptualization of services, a move from a "program paradigm" to a "support paradigm," as a way of bringing resolution to the crisis. He proposes changes in the way we think about people and services, changes in how our programs are staffed and organized, and changes in funding and regulation.

The support paradigm, Smull states, sees people with developmental disabilities as having choices of all sorts, and as getting the support they need to realize their choices. It sees people as participants in community life, with support, taking advantage of opportunities rather than doing what they are told. The support paradigm will mean a "messier" service system, one that encourages the use of the resources of the person, the family, and the community while it uses staff in radically different patterns to carry out the wishes of the people they work for. This paper is worth sending for--Smull expertly delineates the problems with the current community service system and proposes real ways of thinking about solutions to the crisis.

TITLE: Caught in the continuum: A critical analysis of the principle of the least restrictive environment

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1988

Journal of The Association for Persons with Severe Handicaps, 13(1), 41-53.

This article presents a critical analysis of the principle of the least restrictive environment (LRE). The article begins with a review of the origins of LRE in professional writings and law and moves next to a discussion of how LRE has been operationalized in terms of a continuum of residential, educational, and vocational services. Building on previous critiques of the continuum concept, the author presents seven conceptual and philosophical flaws in the LRE principle itself, especially when it is applied to people with severe disabilities. The author warns that an uncritical acceptance of LRE is leading to the establishment of a "new" community-based continuum and argues that many leading writings in the field can be interpreted to legitimate this new continuum. The conclusion of the article briefly contrasts LRE with the concept of integration and supports an unconditional commitment to integration. The article concludes with a note on the importance of viewing concepts in historical perspective.

This article will be most useful to policymakers, professionals, and parent, consumer, and advocacy representatives who are interested in the design of state, regional, or local service systems as well as researchers and others who are involved in the design of service approaches. The article is intended to provide a conceptual and philosophical direction for change, rather than to offer a blueprint for future efforts.

TITLE: Community integration for people with severe disabilities

AUTHOR: Taylor, S. J., Biklen, D., & Knoll, J. (Eds.)

PUBLICATION INFORMATION: 1987

Teachers College Press
Columbia University
1234 Amsterdam Avenue
New York, NY 10027

As people with severe disabilities move from school, family, and institutional environments into community living, work, and recreational settings, the need is growing for ideas, new values, and information regarding community integration. Are yesterday's answers (group living and work environments) still relevant today? This

important book provides a comprehensive review of the issues involved in integrating people with severe disabilities into the community. It establishes a theoretically sound philosophy and policy for community integration, describes and analyzes a number of innovative community-based services, and presents various issues for reconsideration. Reflecting current and emerging issues, trends, and controversies, the book combines theory and practice in a unique and valuable way. This book is an essential resource for policy-makers, parents, professionals, people with disabilities, and those who teach courses having to do with rehabilitation.

Chapter authors include men and women currently involved in the development, restructuring and operation of services. The topics include discussions of the meaning of community integration for people with the most severe disabilities, leadership and staff commitment, gentle teaching, integration in the workplace, and self-advocacy, among others.

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TITLE: Permanency planning for children and youth: Out-of-home placement decisions

AUTHOR: Taylor, S. J., Lakin, K. C., & Hill, B.

PUBLICATION INFORMATION: 1989

Exceptional Children, 55(6), 53-61.

This article addresses "permanency planning" for children and youth with developmental disabilities. After a review of P.L. 96-272, the federal Adoption Assistance and Child Welfare Act of 1980, which mandates permanency planning for children placed out-of-home by social services or child welfare agencies, the authors show how children placed out-of-home by mental retardation and developmental disabilities agencies are denied the protections contained in P.L. 96-272. The authors cite national studies that demonstrate that approximately 48,450 children and youth with developmental disabilities have been placed in foster care and congregate care facilities by agencies not covered by P.L. 96-272. The authors advocate for a revision of P.L. 96-272 to include all children and youth and the incorporation of permanency planning protections and procedures in federal and state programs directed at children and youth with developmental disabilities. They also argue for the adoption of permanency planning as a guiding philosophy for all state and local efforts on behalf of children and youth with disabilities and their families.

This article will be most relevant to people interested in policy issues, including policymakers, federal and state officials, and representatives of consumer, parent, and advocacy agencies. The article provides a starting point for changes in public policy toward children with disabilities and their families, but does not attempt to address the many issues involved in family support services, adoption, and foster care for children and youth.

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TITLE: The nonrestrictive environment: On community integration for people with the most severe disabilities

AUTHOR: Taylor, S. J., Racino, J. A., Knoll, J. A., & Lutfiyya, Z.

PUBLICATION INFORMATION: 1987

Human Policy Press
P.O. Box 127
University Station
Syracuse, NY 13210

COST: $8.95 plus $1.50 minimum shipping and handling

This is a resource manual on community integration for people with severe developmental disabilities. The manual outlines principles for community integration, presents a critique of the "continuum" concept for residential services, describes innovative approaches for supporting children and adults with developmental disabilities in the community, and addresses the importance of commitment, flexibility, and accountability in making integration work. The manual calls for the development of alternatives to group homes and congregate facilities for people with developmental disabilities and argues that children should be supported in natural, adoptive, and foster families and that adults should be supported in their own homes in the community. The Appendix describes practical strategies for community integration and summarizes additional resource materials.

This manual will be most useful to policymakers, administrators, parents, and advocates who are interested in residential and family support services. The manual is written in a popular style and contains many examples of innovative state, regional, and local agencies. Most of the information contained in the manual was collected through site visits to programs in 1985. While some of the information contained in the manual is outdated, this manual provides a foundation for the development of community services for people with severe disabilities.

TITLE: Ideological, political, and legal principles in the community-living movement

AUTHOR: Turnbull, H. R.

PUBLICATION INFORMATION: 1988

In M. P. Janicki, M. W. Krause, & M. M. Seltzer (Eds.), Community residences for persons with developmental disabilities. Baltimore: Paul H. Brookes.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This chapter, written by a father of a young man with severe disabilities, provides a historical context and analysis of the six principles that have contributed to the development of the community living movement. Offshoots of the original principles of normalization, egalitarianism, and equal protection are 1) a new version of parens patriae, which holds that paternalism and altruism are best expressed by moving policy away from institutional placements, 2) anti-institutionalism, which seeks to abolish institutional placement and 3) rebalanced power relationships between professionals and parents, on one hand, and people with disabilities on the other.

The author contends that the offshoot principles, though well-intended, have been misinterpreted in ways that may actually have contributed to the reversal of the original intention to assist people with disabilities. It is suggested that the challenge for the future lies in aggressive advocacy to ensure that improvements in habilitation, integration, interpersonal relationships and client choice become realities.

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TITLE: Images of possibility

AUTHOR: Wertheimer, A.

PUBLICATION INFORMATION: 1986

Values in Action (formally Campaign for the Mentally Handicapped)
Oxford House
Derbyshire
London, England E2 6HG

This report, published in Great Britain, poses themes around the issues we all grapple with related to the future for people with developmental disabilities. It asks, very simply, where we are we going and how we will get there. It systematically presents the issues inherent in the development of "people-oriented" services and describes options that presently exist in the U.S. and Canada. The author discusses lessons that people in Great Britain might draw from the options that are given. The report provides a short yet concise view into relevant topics and questions that we face today, challenging the assumption that people with developmental disabilities can only live with the constant support of special services.

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TITLE: The origin and nature of our institutional models

AUTHOR: Wolfensberger, W.

PUBLICATION INFORMATION: 1975

Human Policy Press
P.O. Box 127
University Station
Syracuse, NY 13210

COST: $5.25 plus $1.50 minimum shipping and handling

A chronicle of the attitudes, hopes and policies that led to the creation of institutions for people with mental retardation, this book explores common perceptions of people with mental retardation, such as pitiable, sick, menacing, innocent, angelic and, only rarely, as developing persons. Too often these attitudes implied a social response that gave rise to massive and inhuman institutions, always isolated from nearby communities. Through historical documents and an original photo essay, we begin to see the nature of institutional life.

The text bears relevance not only for its critique of institutions, but also for its explanations of ideologies and assumptions that underlie them. It is an essential manual for all who would promote deinstitutionalization and the principle of normalization in human services, in local communities, neighborhoods, and workplaces.

TITLE: The principle of normalization in human services

AUTHOR: Wolfensberger, W.

PUBLICATION INFORMATION: 1972

The G. Allan Roeher Institute
Kinsmen Building
York University
4700 Keele Street
Downsview, ON M3J 1P3
CANADA

As one of the most significant publications in the history of human services this book remains necessary reading for anyone involved in the provision of services. The first section delineates the conceptual and historical roots of our society's traditional approach to providing services to people with mental retardation. The principle of normalization is defined and proposed as an alternative service ideology which can avoid the pitfalls of the dehumanizing practices of the past. Some of the major implications of this principle are briefly explored. In the second section the implications of the principle of normalization for a wide range of concerns, from architecture to sex, are explored. The final section explores normalization as an impetus for generic services, citizen advocacy, monitoring of services, and direct financial support for handicapped persons.

ADMINISTRATIVE ISSUES

This division of the Annotated Bibliography consists of three sections dealing with administrative issues:

1. *Planning and Coordination of Services and Supports*
2. *On Funding*
3. *Promoting Quality*

There are hundreds, perhaps thousands, of books and articles on administrative issues, both in general and specific to developmental disabilities services. The resources annotated in these three sections were selected as useful materials for administrators of developmental disabilities services. On the other hand, we believe that administrators must be informed about many more issues then those covered in these sections, and would hope that administrators and others will familiarize themselves with resources that begin with the individual and his or her family and community.

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PLANNING AND COORDINATION OF SERVICES AND SUPPORTS

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The ability of people with the most severe disabilities to live and flourish in the community is largely dependent on the availability of individualized and flexible services and supports. The resources in this section provide conceptual frameworks, service principles, and strategies and resources to use in managing and coordinating a comprehensive system of services. Other materials on planning and coordination of specific services are annotated in the "services and supports" sections.

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TITLE: The closure of mental retardation institutions
I. Trends in the United States
II. Implications

AUTHOR: Braddock, D., & Heller, T.

PUBLICATION INFORMATION: 1985

Mental Retardation, 23(4), 168-176; 23(5), 222-229.

Twenty-four mental retardation institutions in the United States have closed or were scheduled to close in 1985. In Part I, it is pointed out that the closure of institutions is primarily the product of long-term trends toward community services development and economic factors constraining state government expenditures. Part II reviews outcome studies of the impact of closure and involuntary relocation on clients, families, and employees. Interim results of the Dixon Developmental Center Longitudinal Closure Study are also presented, along with suggested closure guidelines

emanating from that study. In conclusion, the implications of institutional closure as an emergent national trend in the field are discussed, and suggestions for future study are delineated.

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TITLE: The Pennhurst Longitudinal Study: Combined report of five years of research and analysis

AUTHOR: Conroy, J. W., & Bradley, V. J.

PUBLICATION INFORMATION: 1985

Temple University
Developmental Disabilities Center
9th Floor, Ritter Hall Annex
Philadelphia, PA 19122

This book provides the results of a five-year study about the Pennhurst litigation (Halderman v. Pennhurst State School and Hospital, 1977) and considers the following aspects: determines the impact of relocation on people with mental retardation; assesses the impact of deinstitutionalization on families; compares the costs of providing services in the institution to those in community settings; assesses the legal history of the Pennhurst case; and addresses various other issues in connection with the disrict court's decree and the implementation. The study is organized into three major parts: 1) A section which assesses the quality of living environments, level of satisfaction and services received by residents both in Pennhurst and in the community. 2) A section which provides average costs per unit of service at Pennhurst and in the community, as well as estimates of total costs for each relocated client as a function of how much service the client actually received. 3) A section which investigates the inter-relationships among events and key system actors, as well as the implications for state and federal policy.

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TITLE: Direction services: A model facilitating secondary prevention of developmental handicapping conditions

AUTHOR: Davidson, P. W., Reif, M. E., Shapiro, D., Griffith, B. F., Shapiro, P. F., & Crocker, A. C.

PUBLICATION INFORMATION: 1984

Mental Retardation, 22(1), 21-27.

This article describes a model program for information, referral, and advocacy for children with or at risk for developing a handicapping condition and their families. The model, implemented and evaluated in Western New York State, ties together the health care and educational-habilitative systems to facilitate a continuity of

comprehensive service provision from birth through school age, increase the total community effort regarding identification, and link identification with the direction counseling and referral process. The model is discussed in terms of its general characteristics, replicability, and its impact on secondary prevention of developing handicapping conditions.

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TITLE: Reuniting families: A resource guide for family involvement in the closing of institutions

AUTHOR: Farlow, D.

PUBLICATION INFORMATION: 1987

Family Support Institute
300-3 East 6th Avenue
Vancouver, BC, V5T 4P4

This booklet is a companion volume to Return to the Community: The Process of Closing an Institution, produced by the Centre for Research & Education in Ontario. It is based on information collected for the study reported on in that volume, and provides hopeful and specific information on reinvolving families whose ties to their family member may have been attenuated or eliminated through a long institutionalization. This book is a must for anyone involved actively in deinstitutionalization, and for those working with people who have left institutions but have little family involvement. The book is written for, and from the point of view of. families but has great relevance for professionals seeking to understand family reluctance and fears about deinstitutionalization.

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TITLE: A new way of thinking

AUTHOR: Governor's Planning Council on Developmental Disabilities

PUBLICATION INFORMATION: 1987

Governor's Planning Council on Developmental Disabilities
State Planning Agency
201 Capitol Square Building
550 Cedar Street
St. Paul, MN 55101

This small manual looks at discussions and changes in Minnesota as representative of new ways of thinking about services for people with developmental disabilities. It discusses the move from an institutional to a community orientation, seeing that as predating the current shift to an individualized approach that focuses on supporting people in regular schools, in their own homes, and in real jobs. It also

presents interesting charts and diagrams illustrating such things as the milestones, nationally, that have led to the newer approaches and a comparison between current and needed federal funding structures. A comprehensive, readable document.

TITLE: Empowering the black family

AUTHOR: Gray, S. S., Hartmen, A., & Saalberg, E. S.

PUBLICATION INFORMATION: 1985

National Child Welfare Training Center
The University of Michigan
School of Social Work
Ann Arbor, MI 48104

This small book presents papers by and a roundtable discussion between Ann Hartman, James Leigh, Jacquelynn Moffett, Elaine Pinderhughes, Barbara Solomon, and Carol Stack. These people came together to discuss ways of delivering preventive child welfare services to Black families, based on a belief that Black children, like other children, are "better off in their own families than in somebody else's family" (p. 11). Their presentations and discussion hit on a multitude of important issues having to do with race in this country: the importance of understanding differences without perpetuating stereotypes, alternative ways of delivering services, the importance of ideology and belief systems, the need to "help clients to learn how to be decision makers as a key empowerment strategy" (p. 30), and many other issues. Developed for social workers, this book could be useful for professionals or policymakers interested in providing better and more effective services to African-American families. There may be more relevant books addressing issues having to do with African-American families, but we have found none in the literature on community integration.

TITLE: Integration of developmentally disabled individuals into the community (Second edition)

AUTHOR: Heal, L. W., Haney, J. I. & Amado, A. N. (Eds.)

PUBLICATION INFORMATION: 1988

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This new edition of a 1980 book has been revised to reflect advances and new assessments of the deinstitutionalization movement. It looks at the socio-political history of the field, reviews ideological and empirical issues, and explores problems

that face policy-makers and advocates. It includes a review of cost-benefit evaluations of residential alternatives, a history of relevant legislation and court cases, a summary of the research literature on training in community and domestic skills, and a challenge to readers looking toward the future.

The book provides a good overview of many of the issues and information known to the field at the time of its revision. It does not, however, deal fully with many of today's most pressing issues, such as how to individualize and support people with developmental disabilities or how to promote and support choices and preferences. This book provides a background for examining the issues of tomorrow.

TITLE: Strategies for achieving community integration of developmentally disabled citizens

AUTHOR: Lakin, K. C., & Bruininks, R. H. (Eds.)

PUBLICATION INFORMATION: 1985, 1988 (revision)

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

This book focuses less on the analysis of the nature of community integration and more on how, in practical terms, to achieve it. Community integration raises a complex web of issues. The authors go a long way toward communicating this complexity and address an extraordinary range of critical issues with uncommon care and detail. The volume examines such issues as the deinstitutionalization policies, the insufficient coordination of services, the lack of opportunities for integrated work, critiques the commonly used behavioral teaching strategies, and looks at model programs in school integration and leisure and recreation. Indicative of the range and relevance of the volume, the editors have sensibly chosen to emphasize economic considerations and the book affords an invaluable superb explanation of federal income/insurance programs demonstrating their penchant to discourage people with mental retardation from entering the work force. It also reveals the complexity of community integration funding strategies and the Medicaid/medical model dilemma.

To our benefit, this volume implores us to ask fundamental questions: about what actually constitutes state-of-the-art; the re-emergence of the medical model; growing bureaucratization of services; the role of professionals in the lives of persons labeled mentally retarded; and the day-to-day experiences of people with severe disabilities.

This book should be of great interest to all who are interested in how to achieve community integration. It provides indepth and far-reaching examination of both the principal, complex barriers to integration and many of the current responses to them.

TITLE: The context of human services planning

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1984

In N. J. Marlett, R. Gall, & A. Wight-Felske, (Eds.), Dialogue on disability: A Canadian perspective. Vol. I: The service system (pp. 1-14). Calgary, Canada: University of Calgary Press.

This chapter explores the values underlying human services that create positive, enhancing experiences for people that use them, critiques traditional human service planning, outlines new perspectives in planning with people who will use services and their families, and proposes new roles for planners. It points out that human service planning typically begins at the top, so that programs are developed before the people to be served have been identified or interviewed as to their preferences and needs. The chapter proposes alternatives to the "top-down" approach and emphasizes integration, inclusion, and choices for individuals as just some of the values that must precede planning, and proposes principles that will lead to innovative, personalized services.

TITLE: Creating responsive communities: Reflections on a process of social change

AUTHOR: Lord. J.

PUBLICATION INFORMATION: 1985

Ontario Association for
the Mentally Retarded
376 Bayview Avenue
Toronto, Ontario M4G 3A3
CANADA

This monograph is about the struggle to create more responsive communities for people with developmental handicaps and their families. In Ontario, Canada, this struggle took the form of ComServ, an acronym for comprehensive, community-based services, a social change strategy developed in 1972. In its simplest form, the goal of ComServ is to provide every handicapped individual with a place in their community where they can go to be assured that high quality services which are comprehensive to their needs will be developed. In another sense, ComServ is about how regions can plan services with individuals and families to ensure that services are valued, individualized, and as integrated as possible.

This monograph has three major sections. Part One documents the history of the ComServ movement in Ontario, including an analysis of the various initiatives

which led people in the 1970s to be concerned about issues which go beyond direct service provision. Part Two provides an analysis and assessment of more recent critical issues and actions from the social change process, including major themes, principles, and processes which have worked and some of those which have faced difficulties. And finally Part Three reflects on how the nature of ComServ has been revised as people's understanding has expanded and as political-economic contexts have changed.

TITLE: Return to the community: The process of closing an institution

AUTHOR: Lord, J., & Hearn, C.

PUBLICATION INFORMATION: 1987

Centre for Research and Education
in Human Services
P.O. Box 3036, Station C
Kitchener, ON N2G 4R5
CANADA

This is an excellent qualitative study of the experiences of people with mental retardation, their families, governmental officials and human service workers involved in the closure of an institution in British Columbia. Throughout the work, ordinary language and dozens of quotations by the people affected are used to discuss and ground the themes that emerged during the course of the study. The findings will be of value to anyone considering change from one form of human service to another, and of special interest to those who are thinking about closing an institution. As readers we are first introduced to the families, residents, and workers and their feelings about and investment in the institution. Next, we move through the process from July 8, 1983, when the government announced the institution would close, to its actual closure 18 months later. Finally, we see how the men and women who left are faring one year later in their services in the community. We see the inadequacy of the planning that usually went into the process, and thereby learn of the importance of careful planning and involvement of families, even families who seem no longer connected to their family member. We learn how eager the families, staff, and community groups were to be involved in the planning, and of the many ways in which some of the parties engaged people in the process. The study documents many weaknesses in the community services that resulted from the process, including their reliance on group homes as the preferred way for people to live in the community and the lack of awareness of the importance of social interaction and social integration for the people who moved back to their home communities. It also documents many benefits of the move for the people affected. This is "must" reading for policymakers and workers hoping to be involved in major social change efforts.

TITLE: Transitions to adult life for people with mental retardation: Principles and practices

AUTHOR: Ludlow, B. L., Turnbull, A. P., & Luckasson, R. (Eds.)

PUBLICATION INFORMATION: 1988

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book covers a wide variety of issues relating to the current services and concepts in transition from school to adult life for people with mental retardation. Most of the chapters are practice oriented. The book focuses broadly on transition from school to adult life and deals with supported employment, community living, and programming goals for educators preparing students for adulthood. It should be of interest to parents, service providers, educators, and policy makers who are involved in transition programs and issues. Appendices include annotated bibliography, media resources and program directory. A good resource for those wishing to plan for adulthood.

TITLE: Do we know enough to plan for transition? A national survey of state agencies responsible for services to persons with severe handicaps

AUTHOR: McDonnell, J., Wilcox, B., & Boles, S. M.

PUBLICATION INFORMATION: 1986

Journal of The Association for Persons with Severe Handicaps, 11(1), 53-60.

This article reflects the research findings of a study which looked at states' abilities to project for and provide necessary numbers of residential and vocational options for severely handicapped individuals in transition from school to adult life. The study, which consisted of the completion of survey questionnaires followed up with a telephone interview, was conducted in forty-four states. The authors note the limitations of the study due to a lack of participation by all agencies in all states, and the time-limited nature of the study. Based on the study the authors identify several national trends relevant to service planning for young adults with severe handicaps in their transition from school to community life. The authors conclude that state agencies responsible for administering community-based work and residential services for adults with severe disabilities are facing a crisis. They also recommend several changes that are necessary at a state and local level if significant progress is to be made in addressing the issue of transition from school to work and community life.

TITLE: Mandate for quality

Volume I. Building on experience: Reviewing common features of systems in Pennsylvania, Michigan and Arizona

Volume II. Missing the mark: An analysis of the Ontario government's Five Year Plan

Volume III. Changing the system: An analysis of New Brunswick's approach

AUTHOR: McWhorter, A., & Kappel, B.

PUBLICATION INFORMATION: 1984, 1985

The G. Allan Roeher Institute
Kinsmen Building, York University
4700 Keele Street
Downsview, ON M3J 1P3
CANADA

The focus of this series is on systems issues, planning, development and implementation, and not on detailed examples of specific program and service approaches. The authors' concern is with systematic approaches related to communities as a whole. The goal of the series is to identify system elements that will enable communities to develop programs of excellence, and to ensure that individuals receive consistent, coordinated and lifelong support from these programs. The series should be instructive to policymakers, state administrators, and advocates.

TITLE: Building community with people with mental handicaps, their families and friends

AUTHOR: Shearer, A.

PUBLICATION INFORMATION: 1986

Values in Action (formally Campaign for the Mentally Handicapped)
Oxford House
Derbyshire
London E2 6HG
ENGLAND

This book is not a blueprint for comprehensive local services to people with mental handicaps and their families. Rather it seeks to provide the impetus for planners and service-providers, professionals and pressure groups, consumers and their

neighbors to be involved together in creating a comprehensive pattern of provision that is truly their own, incorporating the principles of choice-making, individualized services, and consumer participation. The book describes actual examples of these "community initiatives," examples of schemes, services, projects and gatherings together of people committed to enabling people with mental handicaps and their families to share in the ordinary life of their own communities.

The community initiatives are family support schemes that grew in response to local needs and conditions, regular class integration programs in neighborhood schools and 2-year college for children and young adults with severe handicaps. Open employment is available through a community cooperative and two employment agencies. Children and young adults are adopted or find foster homes with ordinary families, while adults stay in ordinary homes, with supports individually designed for them. Leisure activities utilize community resources. Self-advocacy groups are also described.

At the end, the author envisages a future where trained staff will work primarily as coordinators and more "ordinary people" will be involved in the process of incorporating people with disabilities into their own community.

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ON FUNDING

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Although the materials in this section emphasize federal financing of services, especially Medicaid, a number of the materials look also at state, local, and private sector funding sources. Several major resources, on Medicaid, on public expenditures, and on how monies are used and combined by the states, are annotated in this section along with several articles and chapters that discuss the impact of funding sources on services. Other sections highlight resources that describe the funding of specific types of services. For example, the community living sections have resources that describe innovative approaches to, and funding of, community living for children or adults.

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TITLE: Federal policy toward mental retardation and developmental disabilities

AUTHOR: Braddock, D.

PUBLICATION INFORMATION: 1987

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This important book analyzes contemporary federal policies, specifically expenditures for the federal programs for people with mental retardation and developmental disabilities, in the context of their historical development. As the author points out, "Federal programs are rarely created totally anew, but rather are usually grafted to existing statutory and administrative structures." (p. 1). This book provides both this context and an analysis of fiscal trends over time, and is a critical reference for policymakers, professionals, interested laypersons, and students seeking to understand the federal role in providing services, funding research, training personnel, maintaining income, and constructing facilities for people with these disabilities.

The first two chapters provide an overview of the history of federal aid. Chapters three through eight present profiles of each of 82 program elements supported by the federal government since 1935. Chapter nine provides a comprehensive analysis and summary of trends in federal policy, and the book concludes with an epilogue by Gunnar Dybwad, professor emeritus of human development at Brandeis University.

TITLE: The state of the states in developmental disabilities

AUTHOR: Braddock, D., Hemp, R., Fujiura, G., Bachelder, L., & Mitchell, D.

PUBLICATION INFORMATION: 1990

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

During the 1980s, David Braddock and his colleagues have produced national studies of public spending by the states for mental retardation and developmental disabilities services. This book is the third update of these studies, and is the most useful because, in addition to being current and comprehensive, it is hardbound and therefore sturdier than the first two documents. The first section describes the study and provides analyses of spending across states. The second section of the book contains hundreds of charts and other graphics that depict state spending for residential and community services and break down each state's expenditures, revenue sources, population trends, and other critical factors. Charts depicting each state's MR/DD spending per $1,000 per capita income and concise descriptions of the state's programs allow quick comparisons of state efforts and trends. The third section provides supplementary financial and programmatic data, such as state-by-state information on income maintenance programs (federal and state SSI, child disability benefits for adults disabled in childhood), special education services, and vocational rehabilitation services.

This critical reference provides answers to questions regarding where federal and state dollars are going and how states compare with one another, and is the most comprehensive and detailed analysis of public expenditures published to date.

TITLE: Direct cost of institutional care in the United States

AUTHOR: Braddock, D., Hemp, R., & Howes, R.

PUBLICATION INFORMATION: 1986

Mental Retardation, 24(1), 9-17.

The design and results of a nationwide study of the costs of institutional care in the United States between FYs 1977 and 1984 were summarized. Important trends identified were: (a) a plateau in adjusted total nationwide spending for institutional operations, (b) a decline in adjusted nationwide spending for institutions from state revenue sources, and (c) the emergence of the federal government as an equal partner with the states in financing of state institutions. The study also confirmed, through June 30, 1984, the continuing annual reduction in the institutional census and the steady climb in per diems. For the first time, the nationwide per diem exceeded $100 (in 1984).

TITLE: Developing financial incentives for placement in the least restrictive alternative

AUTHOR: Copeland, W. C., & Iversen, I. A.

PUBLICATION INFORMATION: 1985

In K. C. Lakin & R. H. Bruininks (Eds.), Strategies for achieving community integration for developmental disabled citizens. Baltimore: Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

The authors of this chapter suggest that the way most states and the federal government fund services for people with developmental disabilities tends to be uncoordinated and may actually hinder integration. A strong case is made for an approach to funding which is tied to individuals rather than solely to programs. A model state budget is used to show how funds can be redirected in a manner which will support integration.

TITLE: Creative financing of community services: The state agency perspective

AUTHOR: Hemp, R., Braddock, D., Bachelder, L., & Haasen, K.

PUBLICATION INFORMATION: in press

University Affiliated Program
in Developmental Disabilities
University of Illinois at Chicago
1640 West Roosevelt Road
Chicago, IL 60608

Defining creative financing as "coordinating multiple governmental and private sector funding sources in the development and maintenance of effective systems of community services for individuals with mental retardation/developmental disabilities," this monograph presents the perspectives of the principal mental retardation/developmental disabilities agencies in 20 states. The 20 states selected for the survey represented those judged to be most committed to and involved in delivery of community services, and the survey questions focused on the range of services and supports which constitute an "open" community system.

This monograph presents data on states' use of federal, state, and private sector funding sources as well as a series of recommendations for future development. The respondents, most of whom were directors of state offices, identified factors that have encouraged community service development, described state and local factors contributing to funding for community services, and defined federal, state and local governmental and private sector constraints in the development of community services. The responses of these 20 state agencies give cause for hope: it appears that states are looking for ways to promote integration, individualization, and flexibility in funding and service delivery as they work with providers, families, and people seeking services. A subsequent survey and report will address the perspective of private, community-based provider organizations.

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TITLE: Federal administrative constraints on state Medicaid outlays for mentally retarded and other developmentally disabled recipients: A state-by-state survey report

AUTHOR: Gettings, R. M., & Salmon, S.

PUBLICATION INFORMATION: 1985

National Association of State Mental Retardation
Program Directors, Inc.
113 Oronco Street
Alexandria, VA 22314

This is a comprehensive report on the status of federal Medicaid funding of programs for people with developmental disabilities. Based on a review of federal policies, a survey of state officials, and other sources, this report addresses major policy issues in the Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program, the Medicaid home and community-based services waiver program, and other Medicaid programs targeted at people with developmental disabilities. The report contains four major sections. The first addresses federal ICF/MR disallowances. The second section contains an update on home and community-based services waivers and

describes the problems states are facing in having Medicaid waivers approved or extended. The next section describes federal "ICF/MR look behind surveys" designed to monitor compliance with ICF/MR standards. The final major section discusses problems the states experienced in obtaining federal approval for Medicaid reimbursement for clinic, rehabilitation, and personal care services. The Conclusion of the report suggests that expanded federal oversight of the ICF/MR and Medicaid waiver programs may be a "smokescreen" for attempts to reduce federal Medicaid expenditures, rather than to insure high quality services. The appendices of the report also contain listings of state contact persons for obtaining information about various aspects of state Medicaid programs. Written for state mental retardation program directors, this report is an important resource for anyone interested in using federal Medicaid funds to support services for people with developmental disabilities.

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TITLE: An analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) Program

AUTHOR: Lakin, K. C., Hill, B., & Bruininks, R. (Eds.)

PUBLICATION INFORMATION: 1985

Center for Residential and Community Services
Department of Educational Psychology
207 Pattee Hall
150 Pillsbury Drive, S.E.
Minneapolis, MN 55455

This book offers a comprehensive analysis of the Medicaid ICF-MR program, examining the role of Medicaid in providing long term care for people with mental retardation. It offers a historical perspective of the ICF-MR program, as well as legislation and regulations that dictate its implementation. The nature of the present service system is examined, specifically, in relation to the importance of the emergence of non-institutional services presently being proposed as alternatives for individuals funded under Medicaid, offering discussion of contemporary social, philosophical and professional forces re-shaping residential services for people with mental retardation.

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TITLE: Medicaid services for persons with mental retardation and related conditions

AUTHOR: Lakin, K. C., Jaskulski, T. M., Hill, B. K., Bruininks, R. H., Menke, J. M., White, C. C., & Wright, E. A.

PUBLICATION INFORMATION: 1989

Center for Residential and Community Services
Institute on Community Integration
University of Minnesota
207 Pattee Hall, 150 Pillsbury Drive S.E.
Minneapolis, MN 55455

This report describes a major research project funded by the Health Care Financing Administration (HCFA) to examine policy related trends and projections in the use of various Medicaid-funded services for persons with mental retardation and to identify factors influencing these trends nationally and in the various states. The project made a longitudinal analysis of extant data bases on residential services, surveyed all state MR/DD agencies, and prepared case studies of 10 states. This report examines general trends in residential services nationwide, status and trends in intermediate care facilities (ICF-MR), use of the Medicaid waiver (Home and Community-Based Services) in states, placement of people with mental retardation in nursing homes, and the use of other Medicaid options.

A valuable aspect of this report is that it points out that community services have become the norm in most states, and that state directors are interested in expanding and improving community living options. State directors, the report states, are saying that the states need and are seeking expanded federal participation in these endeavors, and are asking for changes in Medicaid, whether in the form of reductions in the restrictions in HCBS requirements or in passage of Medicaid reform legislation. The last few pages of the report detail the problems currently facing states with attention to how the two current Medicaid reform bills respond to them.

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TITLE: The Medicaid home and community-based waiver authority

AUTHOR: National Association of State Mental Retardation Program Directors, Inc.

PUBLICATION INFORMATION: 1981

National Association of State Mental Retardation
Program Directors, Inc.
113 Oronoco Street
Alexandria, VA 22314

Written for state program directors, this is a reference work on the so-called "Medicaid waiver," passed in 1981 to provide federal reimbursement for a broad range of home and community-based services. This report describes the background of the Medicaid waiver, lists the conditions for approval of the waiver, explains eligibility criteria, lists reimbursable services, and provides other information on this funding source for community services. The Appendix contains a copy of federal regulations for the waiver program. This report was written before the federal and state governments had any experience with the Medicaid waiver, and should be viewed as a starting place for exploring the use of Medicaid funds for home and community-based services. Paying for services by Smith and Adelman incorporates much more current information on the states' use of the waiver (annotated on p. 33).

TITLE: Restructuring Medicaid: An agenda for change: Summary Report

AUTHOR: National Study Group on State Medicaid Strategies

PUBLICATION INFORMATION: 1984

Center for the Study of Social Policy
236 Massachusetts Avenue, N.E.
Suite 405
Washington, DC 20002

The study group which wrote this report was formed in 1982 to develop comprehensive strategies to help control Medicaid cost and to increase access to quality service for persons dependent on Medicaid. They review the growth of Medicaid with particular focus on how it grew in totally unintended directions. They call for a radical reordering of this system into two very different systems: 1) a national primary health care program and 2) a continuing care system to meet the needs of individuals with a functional impairment (e.g., the disabled elderly and persons with developmental disabilities). They present a detailed description of these two proposed systems and end by developing a financing plan for both.

Of particular interest to the planner and administrator is this report's analysis of the strength and weaknesses of the current system. What stands out is the inappropriate constraints which Medicaid funding has imposed on the attempts to develop innovative, community-based services for disabled persons. At the very least, reading this report should motivate a thoughtful examination of the way this funding stream has determined the nature of many of our services.

A companion volume of "Background papers" is available from the same source. These papers include: 1) a policy perspective on the Medicaid program, 2) the Provision of Health Services, 3) Policy choices in long term care and 4) the Role of Medicaid in the provision of care for the Developmentally Disabled.

TITLE: Resource allocation approach for determining clients' need status

AUTHOR: Schalock, R. L., & Keith K. D.

PUBLICATION INFORMATION: 1986

Mental Retardation, 24(1), 27-35.

Procedures and exemplary results for a resource allocation approach to determining clients' need status were outlined. Procedures were summarized whereby measured client characteristics can be used to determine whether a client is high, moderate, or low need status based upon a significant relationship between measured characteristics and needed staff time. These characteristics have been identified for Intermediate Care Facilities for the Mentally Retarded and Community-Based Mental

Retardation environments. The authors proposed that this approach results in standard client characteristic data that are helpful in evaluating relevant programmatic, cost, and outcome variables. A number of exemplary uses were presented and potential problems discussed.

TITLE: Paying for services

AUTHOR: Smith, G. A., & Aderman, S.

PUBLICATION INFORMATION: 1987

National Association of State Mental
Retardation Program Directors, Inc.
113 Oronoco Street
Alexandria, VA 22314

This is an extensive and detailed report describing policy, management and technical issues in paying for community services for people with developmental disabilities in the United States. The book discusses trends and directions in community services, including the changing role of the state mental retardation/developmental disabilities agency, gives an overview of how payment systems work, describes reimbursement design and models, and explores management issues. The appendices include examples of models such as case based reimbursement in family supports, supported employment issues and community living payment mechanisms.

The text is primarily directed toward planners and administrators. However, it is a useful reference text for advocates and others who wish to influence their state's direction in the area of payment for community services.

Several journal articles by David Braddock and his associates have examined various aspects of financing. These include:

Braddock, D. (1986). Federal assistance for mental retardation and developmental disabilities I: A review through 1961. Mental Retardation, 24(3), 175-182.

Braddock, D. (1986). Federal assistance for mental retardation and developmental disabilities II: The modern era. Mental Retardation, 24(4), 209-218.

Braddock, D. (1986). From Roosevelt to Reagan: Federal spending for mental retardation and developmental disabilities. American Journal of Mental Deficiency, 90(5), 479-489.

Braddock, D., Hemp, R., & Howes, R. (1987). Financing community services in the United States: Results of a nationwide study. Mental Retardation, 25(1), 21-30.

Braddock, D., Hemp, R., & Fujiura, G. (1987). National study of public spending for mental retardation and developmental disabilities. American Journal of Mental Deficiency, 92(2), 121-133.

Braddock, G., & Fujiura, G. (1987). State government financial effort in mental retardation. American Journal of Mental Deficiency, 91(5), 450-459.

PROMOTING QUALITY

Promoting quality, and ensuring that there are adequate yet nonintrusive safeguards in the lives of people who depend on services, are major concerns for administrators, advocates, parents, and people with disabilities. The paper by John O'Brien annotated in the Perspectives section, What can we count on to make and keep people safe?, addresses many current concerns about how and whether quality can be assured. Some of the materials in this section promote the involvement of a range of reviewers or monitors, while others are instruments that can be used by citizen reviewers. It is most difficult to find quality assurance materials that address the concerns raised in the O'Brien piece mentioned above. The irony is that quality assurance systems cannot assure, and may interfere with, the kinds of lives ordinary people want for themselves. Still, several of these materials acknowledge these problems.

TITLE: Monitoring the quality of life experienced in living arrangements: A guide to citizen participation

AUTHOR: Apolloni, T., Meucci, S., & Triest, G.

PUBLICATION INFORMATION: 1981

California State Council on
Developmental Disabilities
1507 21st Street, Suite 320
Sacramento, CA 95816

This paper provides the rational and a full range of concrete suggestions for establishing and maintaining a citizen monitoring system for community living arrangements. The point is made that citizen monitoring is not a replacement for professional oversight and review but acts as a supplement to these procedures. In particular a voluntary system is able to be sensitive and responsive to issues which professional reviews deal with in only a cursory fashion. Some of the topics covered in this paper are: A) organizing citizen monitoring, B) administration of a program,

C) appropriate umbrella agencies, D) composition of a monitoring committee, E) recruiting members, F) training, G) guidelines for observers, H) follow-up, and I) sources of technical assistance. A model of a service review instrument (to help in structuring observations) is also provided.

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TITLE: Assuring residential quality: Issues, approaches and instruments

AUTHOR: Bersani, H. A.

PUBLICATION INFORMATION: 1989

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $3.40 plus 10% postage and handling

This report contains an overview of major issues in quality assurance, annotated bibliographies of instruments designed to review program quality or integration, and appendices relevant to the issue. Probably of most value to readers will be the annotations of instruments and measures, as these provide a compendium of available instruments, as well as some city and state policy statements, plans, and memoranda.

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TITLE: Monitoring community residences: Guidelines-handbook

AUTHOR: Bersani, H. A.

PUBLICATION INFORMATION: 1984

ARC - Ohio
751 Northwest Boulevard
Columbus, OH 43212

These two resources are primarily intended to be used in conjunction with a day-long training session for voluntary service monitors. The Handbook is a resource for the monitors and the Guidelines is the actual monitoring instrument. The basis for this approach to monitoring is the sense that volunteer and parent monitors will view programs from a perspective which is very different from that of the professional auditor. The Handbook defines the role of the monitor and clarifies the meaning of normalization. The Guidelines provide a list of questions to be answered by the monitor as they relate to the following issues in residential settings: 1) rights; 2) the environment, physical and social; 3) use of community resources; 4) commitment to personal growth; and 5) staff. Both volumes contain useful bibliographies.

TITLE: Quality assurance for individuals with developmental disabilities: It's everybody's business

AUTHOR: Bradley, V. J., & Bersani, H. A. (Eds.)

PUBLICATION INFORMATION: 1990

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This edited book presents current, often divergent, perspectives on quality assurance. As Elizabeth Boggs points out in the foreword, the book does well at reflecting the chaos in the field of developmental disabilities. If quality assurance is everybody's business, how can the varying perspectives of all the players be reconciled? One very positive feature of the book is its inclusion of consumer and family members' perspectives. These chapters challenge readers to consider how consumers and family members can be meaningfully involved in assessing and assuring the quality of the services they receive. Other chapters address governmental, management, advocacy and accreditation issues, research, and quality assurance systems. A final chapter on the future points to the possibility of developing responsive quality assurance systems, of moving away from the present systems' reliance on basic regulatory approaches, far removed from the people whose lives are affected.

TITLE: Assessing and enhancing the quality of services: A guide for the human service field

AUTHOR: Bradley, V. J., et al.

PUBLICATION INFORMATION: 1984

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This report should be must reading for anyone concerned with quality assurance. There are solid discussions of both the philosophical and practical issues in this area, as well as the description of numerous successful programs.

A primary focus of this report is the development of a cost effective system of quality assurance which goes beyond "paper" compliance and yet remains flexible enough to allow the growth of innovative services. A critique of the current system is offered. A theoretical framework which conceptualizes quality assurance as having five major components that have implications at both the policy and the operational level is outlined. The authors provide a good discussion of the complimentary roles

played by citizens, volunteers, professional peer monitors, private evaluators, consumers, families, advocates, and accreditation organizations in the assurance of quality services. The analysis of eight specific techniques of monitoring are organized according to the auspices under which they are best carried out. The description of each technique includes an assessment of its uses, limitations, and applicability to specific situation. Chapter 4 is targeted on the regional official or private funded who is looking for a systematic procedure for analyzing and redesigning their quality assurance programs. The final section describes 22 quality assurance programs. It discusses each program's purpose, scope, implementation history, monitoring process, analytic process, control process, strengths, and limitations.

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TITLE: Options policy on quality of life

AUTHOR: Options in Community Living

PUBLICATION INFORMATION: 1983

Options in Community Living
22 North Second Street
Madison, WI 53704

Options in Community Living, a support service agency for adults living in the community (see annotation for Belonging to the community, page 76), prepared this policy statement to provide staff with standards for evaluating the well-being of people they support and for identifying areas where intervention might be needed. The policy statement is available as part of the manual, Belonging to the community. It covers areas such as personal income, housing, health, safety, appearance and hygiene, relating with others, meaningful activities, and mobility. For each of these areas, the policy identifies conditions that must exist to ensure that a person will not be at risk in the community and conditions that will further promote a valued lifestyle.

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TITLE: A guide to program quality review of day programs (Second ed.)

AUTHOR: Rammler, L.

PUBLICATION INFORMATION: 1986

State of Connecticut
Department of Mental Retardation
90 Pitkin Street
Hartford, CT 06108

This quality assurance instrument includes six sets of measures of program quality, including: a) presence and participation measures; b) good relationships measures; c) choice measures; d)respect and dignity measures; c) competence

measures, and f) wages and benefits measures. These measures, based on the Connecticut Department of Mental Retardation's overall mission statement, promote values that the department, parents, and people with disabilities in Connecticut identified as important in peoples' lives. The guide includes explanations as to how each question should be applied to a program.

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TITLE: Quality of life: Perspectives and issues

AUTHOR: Schalock, R. L. (Ed.)

PUBLICATION INFORMATION: 1990

American Association on Mental Retardation
1719 Kalorama Road, NW
Washington, DC 20009

This book addresses quality of life from a variety of perspectives, including that of quality assurance. A major section at the beginning presents personal perspectives--chapters by a parent, a sister, two people who have received services, and two written by professionals who reflect on quality of life from the point of view of the person who lives it. A second section discusses service delivery issues, looking at different stages in the lifespan and at work, home, and community participation. Third, four chapters look at assessment and measurement issues, including how to conceptualize quality of life for the purpose of measuring it. A final section deals with legal, philosophical, historical, and future perspectives. A number of the authors suggest that the quality of life concept can serve to unify and make coherent disability policy, because the concept deals with concerns that are important to everyone involved, not just the funders. In a concluding chapter, Schalock presents a series of values-based quality of life principles to guide policy and research efforts. This interesting and thoughtful book raises, but does not necessarily resolve, a number of troubling questions.

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TITLE: Observing community residences

AUTHOR: Taylor, S. J., & Bogdan, R.

PUBLICATION INFORMATION: 1980

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $1.00 plus 10% postage and handling

This brief, 13-page guide explains how and what to observe at community residential settings. It is not a checklist or evaluation instrument. Instead, this guideline lists an exhaustive set of questions to have in mind when visiting settings. Specific sections include: Location, building and yard, relations with the neighborhood, admission, operation, interior, habilitation and treatment, staff, residents, staff and resident communication, vocabulary, daily routines, clothing, personal appearance and hygiene, personal possessions, residents' rights, control, relations with family members, and records. This guide can be used to help parents, consumers, and citizens to monitor residential settings and to sensitize new staff members, parents, and others to features of a setting that enhance or detract from the quality of life.

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TITLE: Quality assurance resources: Instruments, organizations, and publications

AUTHOR: Wieck, C., Nelson, J., Reedstrom, C., Starr, J., & Stone, N.

PUBLICATION INFORMATION: 1989

ARC-US
P.O. Box 6109
Arlington, NJ 76005

This book lists and describes quality assurance instruments, organizations, and publications to lead citizens to resources for monitoring services. The ARC-US position on quality is stated at the beginning of the booklet, emphasizing a multidimensional system for ensuring quality. Each resource is described, along with ordering information and cost.

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TITLE: PASSING: Program analysis of service systems' implementation of normalization goals

AUTHOR: Wolfensberger, W., & Thomas, S.

PUBLICATION INFORMATION: 1983

The G. Allan Roeher Institute
Kinsmen Building, 4700 Keele Street
York University
Downsview, ON M3J 1P3
CANADA

This book provides the guidelines for operationalizing the principle of normalization in an instrument for evaluating the quality of human services. In addition, the specific examples and discussion contained in this manual are intended to teach the principle of normalization to human service workers. The 42 PASSING

ratings are broken down into two major categories: 1) Program elements related to client social image enhancement and 2) elements related to competency enhancement. Within both categories ratings are further subdivided as to whether they apply to a) the physical setting in which the service is located; b) the ways in which the service groups its clients and otherwise structures and supports relationships between them and other people; c) the activities, programs, and other ways in which the service structures the clients time, and d) miscellaneous other factors including language, symbolism, and imagery which the service attaches to its clients. All in all, the indepth analysis encouraged by this resource guides the reader through a rigorous examination of any service setting.

PLANNING WITH INDIVIDUALS

This section focuses on planning with, as well as on behalf of people for whom supports and services are being designed. Traditional approaches to "individualized planning" tend to impose structures on the individual: IPPs or IHPs or IEPs are developed by professionals, based on assessments of individual deficits and strengths, sometimes with the "involvement" of the person or the family. Today, we recognize the importance of starting with and staying with the choices or preferences of the person, and of planning the services and support, from that base, so that the person and/or the family retain maximum control and there are many who are discussing issues having to do with placing the power and responsibility in their hands rather than with professionals. The materials in this section address various aspects of this concept including assessment, skill development, choice-making, case management, personal futures planning, and guardianship. This section represents a beginning look at planning with individuals, as more and more materials are being developed every year. Also, please see specific sections for additional materials related to particular services and supports. Many of the best descriptions of various services incorporate discussions of the individualized planning process.

TITLE: Principle of partial participation and individualized adaptations in education programs for severely handicapped students

AUTHOR: Baumgart, D., Brown, L., Pumpian, I., Nisbet, J., Ford, A., Sweet, M., Messina, R., & Schroeder, J.

PUBLICATION INFORMATION: 1982

Journal of The Association for Persons with Severe Handicaps, 7(2), 17-27.

In distinction from earlier models of instruction for severely handicapped individuals which generally seemed to regard the attainment of complete independence and total mastery of all aspects of a task as the only appropriate education goal, this article posits the value of partial participation and task adaptations. It affirms that all severely handicapped persons can acquire many skills that will allow them to function, at least in part, in a wide variety of non-segregated school and nonschool environments and activities. Six types of individualized adaptations are delineated. Clear guidelines for deciding when the use of partial participation and adaptations is appropriate are provided. And finally, an eight phase strategy for implementing this approach in any setting serving persons with severe disabilities is discussed.

TITLE: Getting to know you: One approach to service assessment and planning for individuals with disabilities

AUTHOR: Brost, M. M., & Johnson, T. Z.

PUBLICATION INFORMATION: 1982

DHSS-DCS
P.O. Box 7851
Madison, WI 53707

This book describes one attempt to create an alternative approach to needs assessment and service planning for people with developmental disabilities. The authors don't believe that knowledge or understanding of a person's needs can be gained through administration of interview schdules, checklists or any other standardized procedures (most widely used in human services today). Instead they have developed an alternative and manageable way of gathering information that avoids treating people routinely or losing track of their uniqueness. This alternative approach to individual assessment and planning offers very helpful guidelines to insure that the services that are planned, purchased and delivered really respond to the individual's need.

The book is divided into two parts: Part I contains a description of the approach to need assessment and planning that was developed and refined during 1979-1981 by staff of the Developing Individualized Service Option Project, Wisconsin. Part II describes and critiques a training project carried out in LaCrosse, Wisconsin to teach people to use the need assessment and service planning process described in Part I.

The book is a very useful handbook for people whose jobs involve assessment/planning and for people involved in training others in assessment and planning. Much of the material is also a valuable resource for others, such as direct service providers, advocates, administrators, parents and consumers.

TITLE: Using the characteristics of current and subsequent least restrictive environments in the development of curricular content for severely handicapped students

AUTHOR: Brown, L., Branston-McLean, M. B., Baumgart, D., Vincent, L., Falvey, M., & Schroeder, J.

PUBLICATION INFORMATION: 1979

Journal of The Association for the Severely Handicapped, 4(4), 407-425.

The article presents an overview of integrated programming for students with severe disabilities. The main pieces of the argument are: (1) people with severe disabilities should not be compared with younger, non-handicapped people; (2) programs for students with severe disabilities should use various adaptations to insure at least partial participation in chronologically age-appropriate, functional activities; (3) these programs should be future-oriented and affirmative (oriented to "current and subsequent environments"); (4) the article argues that services for should be varied, individualized, hetereogeneous, flexible, evolving and able to change. In addition, it gives strategies and steps to achieve these objectives. The examples about the importance of integration with non-handicapped people are particularly effective. Emphasis is upon personal dignity and self-esteem, along with the necessity to perform portions of skill sequences in functional ways.

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TITLE: Choices and obligations: A look at personal guardianship

AUTHOR: Centre for Research and Education in Human Services

PUBLICATION INFORMATION: 1988

Centre for Research and Education in Human Services
P.O. Box 3036, Station "C"
Kitchener, ON N2G 4R5
CANADA

This, one of a Centre series of Policy Analysis Papers, is based on a day long meeting coordinated by the Centre for Research & Education in Human Services. The group in attendance represented consumers, parents, service providers, advocates, and community researchers as well as board members and staff of the Centre. As such, this paper presents a philosophical overview of the reasons for, dilemmas inherent in, and abuses occurring with the legal procedures known as guardianship. While Canadian law may differ from guardianship law in any given state in this country, many of the issues and dilemmas surrounding guardianship hold true here as well. Thus, this short paper is valuable because it frames these issues, discusses when and why intervention in an adult's life might be considered, and points out the complexities of establishing what is in the best interest of another.

Another good aspect of this paper lies in its discussion of the limitations of legislation and its exploration of the idea that expanded policies and community initiatives to create more responsive communities must accompany effective, nonintrusive guardianship legislation. It points out the many times in which nonguardianship responses are more appropriate and protective of individual rights than an automatic presumption of incompetency, and the many safeguards that should be employed if guardianship is used. The paper concludes with a variety of suggestions for guardians, policymakers, judges, and others concerned with the issues surrounding guardianship.

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TITLE: Community instruction: A natural cues and correction decision model

AUTHOR: Ford, A., & Mirenda, P.

PUBLICATION INFORMATION: 1984

Journal of The Association for Persons with Severe Handicaps, 9(2), 79-88.

In this article the authors provide the direct service worker in community educational, vocational, and residential programs with a clear, concise outline of a skill development decision model. What is significant about this model is that it specifically focuses on the special problems which arise when instruction is undertaken in the non-laboratory conditions of real community environments. As opposed to much other work in special education literature the author's intent is to use naturally occurring cues and corrections and not artificially contrived behavioral interventions. This is a fine "how to" article which avoids the trap of merely telling the audience how one discrete intervention was carried out.

TITLE: Concepts and issues related to choice-making and autonomy among persons with severe disabilities

AUTHOR: Guess, D., Benson, H. A., & Siegel-Causey, E.

PUBLICATION INFORMATION: 1985

Journal of The Association for Persons with Severe Handicaps, 10(2), 79-86.

This article is considered by some to be a classic discussion of the issues of choice and autonomy in the field of disability, as it relates to persons with significant needs.

Guess discusses how important it is for all of us to make decisions and choices in our lives: "The opportunity to make choices reflects favorably on one's perceived independence, dignity, and self-worth" (p. 79). Yet, these skills are not often being taught in educational programs for persons with disabilities. Guess cites Holvoet, et al. (1983) on this point: "...opportunities to make choices, decisions, and express preferences are conspicuously absent from educational programs for persons who are handicapped." Historically teachers and service providers have assumed that they know what will enable persons with disabilities to function in society.

The authors delineate three levels or categories of choice, including: a) preferences, b) choice as a decision-making process, and c) choice as an expression of autonomy and dignity.

TITLE: The family as care manager: Home care coordination for medically fragile children

AUTHOR: Kaufman, J., & Lichtenstein, K. A.

PUBLICATION INFORMATION: 1986

Coordinating Center for Home and Community Care, Inc. (CCHCC)
P.O. Box 613
Severn Professional Building
Millersville, MD 21108

This workbook is an extremely valuable tool for parents and families who choose to care for their "medically fragile" child at home. Written clearly and concisely, it provides necessary and practical organizational information, as well as being an educational and informational resource tool.

Divided into four sections, Section I, the "Introduction," gives a brief review of what is entailed in a discharge plan, a very thorough needs assessment to be completed by the family, and a redefinition of "care manager." Section II, "Families as Care Managers," describes the five roles which families must assume as care managers: the role of medical manager, financial planner, educational advocate, resource specialist, and employer. Included within each topic are practical checklists and worksheets. Section III, "Maintenance of Records," explains the need for families to maintain an organized system of record keeping and delineates which information to include in an open file. Section IV, "Conversation with Families: Recurring Themes," lists those themes and concepts that the authors found to be common to families exploring the "home care frontier."

TITLE: Service coordination: A systems approach to medically fragile children

AUTHOR: Kaufman, J., Lichtenstein, K. A., & Rosenblatt, A.

PUBLICATION INFORMATION: 1986

Caring, 62, 42-46.

In this article the role of service coordination is offered as a necessary alternative to traditional case management in services for "technology-assisted" or "medically fragile" children. The description presented here is based on the experience of implementing this role under the Maryland Medicaid waiver. Within this system the coordination role includes responsibilities for screening, assessment, planning, cost effectiveness, supporting informal support systems, and on-going monitoring. The specific role of clinical care coordinator and financial coordinator are described in some detail. Issues in cost containment and determining cost effectiveness are discussed. A model cost effectiveness worksheet is provided.

TITLE: The case management team: Building community connections

AUTHOR: Lippert, T.

PUBLICATION INFORMATION: 1987

Developmental Disabilities Program of
The Metropolitan Council
300 Metro Square Building
Seventh and Robert Streets
St. Paul, MN 55101

This excellent monograph presents ideas on how families, case managers, service providers, public officials and advocates can better understand and promote community integration of people with disabilities. The book describes a vision of an integrated society, discusses five elements of case management (i.e., assessment, planning, monitoring, evaluating and advocating), explores the changing role of case management (including the area of community connections) and examines barriers to social change. The appendices include a variety of sample plans, policies and materials focused on promoting quality lives for people with disabilities. This is an exceptional resource, clearly written, visually well presented and usable by a broad audience.

TITLE: It's never too early, it's never too late: A booklet about personal futures planning

AUTHOR: Mount, B., & Zwernik, K.

PUBLICATION INFORMATION: 1988

DD Case Management Project
Metropolitan Council
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

Publication No. 421-88-109

The authors note in the introduction that this booklet is an attempt to describe what personal futures planning is, but not to provide "instruction on how actually to do it." (p. 1) The booklet does contain an overview of the personal futures planning process, describing it as "more than just a plan; it is an ongoing problem-solving process." The underlying assumptions of personal futures planning are outlined along with how personal futures planning differes from the traditional planning efforts that are used in Minnesota. The authors suggest ways that these two approaches can be

combined. The material is brought to life with a number of personal examples found in the text, accompanying pictures and graphics.

When people with disabilities have been failed by the human service system and are not supported to take part as much as possible in the everyday life of the community around them, personal futures planning represents one way for families, friends, and advocates to establish an alternative vision. But, as the authors caution, the support that can come from this particular process must be voluntary, and cannot be mandated nor simply turned over at a later date to service providers.

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TITLE: Framework for accomplishment: A workshop for people developing better services

AUTHOR: O'Brien, J., & Lyle, C.

PUBLICATION INFORMATION: 1988

Responsive Systems Associates
58 Willowick Drive
Decatur, Georgia 30038
(404) 987-9785

This is an excellent week-long workshop for service providers and others interested in developing better ways of supporting people to live in the community. The workshop emphasizes accomplishments and valued experiences that apply to most people in our society, and leads the participant to discover ways of supporting one person to achieve these accomplishments and experiences. Participants work in teams, each participant in a team getting to know one person with a disability. The team develops profiles for desired futures for the people they have come to know, and works together to define constructive actions that could be taken by the program serving that person. This is an intense and creative experience, very enjoyable for participants and for the agencies that volunteer as sites for the workshop. The manual for the workshop cannot be purchased separately.

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TITLE: A handbook for people thinking about moving

AUTHOR: People First of Washington

PUBLICATION INFORMATION: 1990

People First of Washington
P.O. Box 381
Tacoma, WA 98401
(206) 272-2811

People with developmental disabilities who are thinking about--or being projected for--a move from one place to another (nursing home or institution to community, group home to apartment, etc.) may need assistance in making informed choices about the options available to them. This handbook can be used by anyone, including a member of a self-advocacy group, to help someone understand and decide about a new home. The user goes through a process that includes four steps: 1) knowing one's rights about moving; 2) making a list of what one wants in life; 3) looking at, visiting, and comparing all the choices to what one wants; 4) making a decision without pressure. The handbook is laid out for use as a workbook, so that users could write in it as they go through the steps. It could also be used by an individual's family and friends, if they are needed to help with the decision-making process. Each step asks a large number of concrete questions that should help users develop a vision of what is wanted and to compare that vision with an actual place. While this handbook uses a few Washington terms, it is nevertheless an excellent resource for anyone interested in planning with an individual with developmental disabilities.

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TITLE: Service brokerage: Individual empowerment and social service accountability

AUTHOR: Salisbury, B., Dickey, J., & Cameron, C.

PUBLICATION INFORMATION: 1987

The G. Allan Roeher Institute
Kinsmen Building, 4700 Keele Street
Downsview, ON M3J 1P3
CANADA

Service brokerage, a concept that has been discussed for years, has been operationalized in British Columbia and is described in this small manual. In British Columbia, the concept was developed by parents of people with disabilities and is based on the belief that the standard ways of providing and funding services are inadequate. Service brokerage attempts to make systems more accountable to the people served by them and to put decision-making control in the hands of these people and their support networks. As the booklet describes, brokerage is one dimension of a "support nucleus" consisting of three components. Within this nucleus, "service brokerage is the technical arm of an autonomous planning mechanism that is community-based and consumer-controlled" (p. 1). The service broker works within this planning process, offering brokerage services (e.g., assisting the person to purchase support services to live in a home of his choice) that are linked to individualized funding which ties dollars to the individual.

U.S readers will find the brokerage concept, the planning mechanism, the emphasis on personal support networks, and the description of individualized funding of great value as they reconceptualize services provided in this country.

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TITLE: The importance of choice-making skills for students with severe disabilities

AUTHOR: Shevin, M., & Klein, N. K.

PUBLICATION INFORMATION: 1984

Journal of The Association for Persons with Severe Handicaps, 9(3), 159-166.

This article raises the important issue of allowing persons with severe disabilities to have real opportunities to make choices. The authors contend that because of the degree of their disabilities and the nature of the environments within which they function it is necessary: 1) to specifically teach persons with severe disabilities culturally normative ways to express their choices, and 2) to structure activities to enable them to exercise choice. Procedures are suggested for teaching choice-making skills, for integrating opportunities for exercising those skills throughout the day, and for fostering choice-making skills through the use of logical consequences. As with many JASH articles this article is written in terms of educational programming, but the points made here certainly have utility in any setting which provides services to severely disabled individuals.

TITLE: Enhancing nonsymbolic communication interactions among learners with severe disabilities

AUTHOR: Siegel-Causey, E., & Guess, D.

PUBLICATION INFORMATION: 1989

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285

This book is based on the premise that there will be reciprocal communication between service providers and people who may not have the use of spoken language. The book has three objectives: to assist the service provider to better understand nonsymbolic communication, to assist the person with severe and multiple disabilities to expand nonsymbolic expressions, and to encourage this form of exchange. The book is important because it emphasizes the mutuality of communication, affirms the communication methods of people with multiple disabilities, and provides a foundation for further work on understanding the choices and preferences of people with multiple disabilities.

TITLE: Case management in long term care programs

AUTHOR: Simpson, D. F.

PUBLICATION INFORMATION: 1982

Center for the Study of Social Policy
236 Massachusetts Avenue, N.E.
Suite 405
Washington, DC 20002

This report is a valuable resource for anyone attempting to understand or define the role of the human service case manager. This report provides an overview of how case management has been defined as a necessary service in response to the increasing complexity of a community-based service system. The diverse roles (from client advocate to service coordinator to cost containment officer) which have been assigned to the case manager are outlined. Twelve (12) federal projects, which defined the case management role in different ways, are discussed in detail with emphasis on the strengths and weaknesses of the particular model of management utilized in each instance.

TITLE: The activities catalog: An alternative curriculum for youth and adults with severe disabilities

and

A comprehensive guide to the activities catalog: An alternative curriculum for youth and adults with severe disabilities

AUTHOR: Wilcox, B., & Bellamy, G. T.

PUBLICATION INFORMATION: 1987

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

A single copy of The activities catalog is sold together with A comprehensive guide to the activities catalog. Additional copies of The activities catalog can be purchased in sets of three by contacting the Brookes Publishing Company.

The activities catalog is a functional handbook, for parents, friends, teachers and other service providers of individuals with developmental disabilities, that focuses on teaching general lifestyle activities. The catalog examines a wide array of activities

in the areas of leisure, vocational skills acquisition and activities of daily living. An emphasis on real life experiences and realistic step-by-step learning emerge as the preferred teaching tools.

The accompanying book, A guide to the activities catalog, is useful for professionals concerned with the development of assessment, intervention and evaluation methods. The guide is also helpful for anyone who is interested in a background discussion of the innovative teaching methods, which are outlined and suggested as alternatives to more traditional methods of teaching lifestyle skills.

TITLE: Moving persons with developmental disabilities toward less restrictive environments through case management

AUTHOR: Wray, L., & Wieck, C.

PUBLICATION INFORMATION: 1985

In K. C. Lakin & R. H. Bruininks (Eds.), Strategies for achieving community integration for developmentally disabled citizens (pp. 219-230). Baltimore: Paul H. Brookes.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

The authors take the position that effective case management is "the glue which holds together" a community based services system. They see this role as supporting natural networks, providing for flexibility, effecting true individualization, offering real choices, and enforcing cost efficiency. They further suggest that only by exploring the potential of the case manager can dollars actually be brought to follow individuals rather than programs. Various definitions of case management are explored. The elements which are identified as central to effective service are a well-defined process, clear-cut responsibilities, good information about clients and services, inter-agency agreements, and adequate resources.

SERVICES AND SUPPORTS FOR INTEGRATION

The resources in this division are grouped together becuase they deal directly with services and paid or formal supports, rather than with informal supports and advocacy. They also promote, in general, integration and community participation.

They are divided into the following sections:

1. *Community Living for Children*
2. *Community Living for Adults*
3. *Education in the Regular Classroom*
4. *Integrated Employment: Services and Supports*
5. *Recreation and Leisure*
6. *Supporting People with Challenging Behaviors*
7. *Supporting People with Complex Physical and/or Health Needs*

We believe that readers should approach these sections with an additional commitment to explore resources on community, relationships, and other issues basic to all of our lives.

COMMUNITY LIVING FOR CHILDREN

Children with disabilities should have the same kind of life that is possible for children without disabilities. This means life in a family, either the family into which they are born or another permanent family. In many ways, the philosophy and concept of permanency planning and family support encompass each other. The supports needed by birth families are also needed by foster and adoptive families, and permanency planning ideas apply to children and their birth families as well as children in out-of-home placements (see Taylor, Lakin, & Hill, Permanency planning for children and youth: Out-of-home placement decisions annotated on page 57). This section, therefore, contains materials on family support services and on permanency planning, and we ask the reader to consider them together.

FAMILY SUPPORT

This subsection includes brief annotations of some resources on family support. There is a rapidly growing body of literature available today on family support; hence, the material covered here only represents a small portion of that which exists. This listing includes some of the materials that describe current and innovative trends in family support.

TITLE: Family care for persons with developmental disabilities: A growing commitment

AUTHOR: Agosta, J. M., & Bradley, V. J. (Eds.)

PUBLICATION INFORMATION: 1985

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

The report includes five concept papers on family support issues, including a parental perspective, the perspective of a person with a disability, an overview of the goals and purposes of family support services, a review of current options for family support policy, and a future policy directions statement. The appendices include a directory of 22 statewide family support initiatives and 11 organizations that offer parents financial planning services.

TITLE: Designing programs to support family care for persons with developmental disabilities: Concepts to practice

AUTHOR: Agosta, J., Bradley, V., Rugg, A., Spence, R., & Covert, S.

PUBLICATION INFORMATION: 1985

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This report on family support services highlights the trends in the literature, presents the results of a 50 state survey (with case studies of six of the states), and includes information on the development of a family support policy in Virginia. Six key issues surrounding the development of family support services are discussed including the role of the family, program eligibility, service administration, permissible services, use of existing resources and facilities, and program evaluation.

The report is written primarily for professionals and service planners who are interested in the status of family support service programs in this country and in the major issues involved in their development.

TITLE: Site visit report: Calvert County, Maryland ARC family support services

AUTHOR: Bersani, H. A., Jr.

PUBLICATION INFORMATION: 1987

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $1.95 plus 10% postage and handling

This report describes family supports provided by the Calvert County ARC. The major types of supports offered include: in-home companions; out-of-home respite at a respite worker's home; respite at an integrated day care center; parent counseling; parent support groups; financial support; and information referral and service coordination. Families pay for services on a sliding scale, based upon their ability to pay.

In its approach to families, the agency begins by asking "what would make a difference?" Program staff are committed to integrated community and family life for all children regardless of their level of disability, and are willing to do "whatever it takes" to support children and their families.

TITLE: Keeping your child at home: The case for family supports

AUTHOR: Bradley, V., & Agosta, J.

PUBLICATION INFORMATION: 1985, November

Exceptional Parent, 15(7), 10-22.

This paper discusses the need for family support, the philosophical basis for family support, and barriers to providing family support. It includes results from a survey describing what types of family support programs (cash assistance, supportive services, or combination) existed in each state in 1985, and the strengths and weaknesses of each approach. The paper concludes with a brief but detailed description of the family support program and Family Subsidy Act in Michigan.

TITLE: Policy options for family support services

AUTHOR: Castellani, P. J.

PUBLICATION INFORMATION: 1985

New York State Office of Mental Retardation
and Developmental Disabilities
44 Holland Avenue
Albany, NY 12224

The first section of this paper reviews the background to development of family support services, describes the array of services offered in 17 states, and discusses the need to develop family support services that "directly support and strengthen the family." The second section discusses eligibility issues from a policy perspective, as well as reviewing eligibility criteria in the 17 states surveyed. Part three discusses delivery of family support services, including the need for local/regional responsibility for programs, and the importance of service delivery based on families needs. Section four discusses funding of family supports, including the potential for Medicaid waiver funding.

TITLE: Families who care for severely disabled children at home: A public policy perspective

AUTHOR: Cina, S., & Caro, F. G.

PUBLICATION INFORMATION: 1984

Institute for Social Welfare Research
Community Service Society of New York
105 East 22 Street
New York, NY 10010

This paper focuses on family supports in New York City. It begins, however, with a general overview of current public policy regarding people with developmental disabilities and of various means of financing health care and support services (including private insurance, Medicaid, Title XX, Crippled Children's Services, the SSI Disabled Children's Program, and through voluntary agencies). The report includes discussion of the impact of long-term home care on families; what types of supports families need; what types of supports are currently being provided; and what else can be done. It concludes with a number of strategies to increase support for families, including greater flexibility in funding (i.e., through subsidies, voucher systems, etc.); revision of federal tax laws; and, an increase in the range of support services that are available to families.

TITLE: Respite care: Supporting families of developmentally disabled persons

AUTHOR: Cohen, S., & Warren, R. D.

PUBLICATION INFORMATION: 1984

Pro ED
5341 Industrial Boulevard
Austin, TX 78735

This book provides a comprehensive coverage of all aspects of respite care. As such, it addresses why respite care is needed, what functions it serves, and what research has to tell us about respite care. Effective models of respite care are given. Also covered are the selection and training of respite care workers, legal and fiscal perspectives, how to start and operate a respite care program, issues and problems, and respite care for families of the elderly, the terminally ill, and other dependent populations.

TITLE: Family support programs for families who have children with severe emotional, behavioral or mental disabilities: The state of the art

AUTHOR: Freud, E.

PUBLICATION INFORMATION: 1990

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This monograph identifies and explores various approaches to supporting families having children with severe emotional disorders, a group that has traditionally been ignored in discussions of family support. Identifying the core components of family support as self-help, advocacy, parent education, respite care, family centered case management, and cash assistance, the monograph profiles nine programs in seven states. A discussion of the future of family support for this group of families concludes the monograph.

TITLE: Family support: A challenge for the 1990s

AUTHOR: Knoll, J.

PUBLICATION INFORMATION: 1990, June

Exceptional Parent, 20(4), 28-34.

This article summarizes information gathered by the Human Services Research Institute on family support services in every state and discusses trends in family support. A state-by-state chart condensing this information appears at the back of the article along with a directory of state family service programs. This is a good resource for parents, as it describes the challenges facing most state programs and proposes an ideal that is seldom yet realized: a fully available array of parent-controlled, family-centered, community-focused supports.

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TITLE: Family support services in the United States: An end of decade status report

AUTHORS: Knoll, J., Covert, S., Osuch, R., O'Connor, S., Agosta, J., & Blaney, B.

PUBLICATION INFORMATION: 1990

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This monograph presents the results of a comprehensive telephone survey of officials in every state regarding the "state of the states" in family support policy. The authors propose a definition of family support that includes 14 principal components (dozens of discrete services might be included in any state's plan) and provide information on where each state stands in relation to these components. Additionally, profiles of every state's efforts in relation to family support are provided. An excellent source of current information, this monograph should assist family members, advocates, administrators, and policymakers to assess their own state's programs in relation to others and to visualize what is needed to develop comprehensive supports for families.

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TITLE: Michigan Department of Mental Health report on Family Support Subsidy Program FY 85-86

AUTHOR: Parrott, M. E., & Herman, S. E.

PUBLICATION INFORMATION: 1987

Michigan Department of Mental Health
Lewis Cass Building
Lansing, MI 48926
(517) 373-2900

This paper describes Michigan's family support subsidy program in detail. The subsidy is one piece of an overall policy of family preservation which includes family supports and permanency planning. Permanency planning is the philosophy which provides the framework for service delivery. The underlying assumption in permanency planning is that children need parents, a home, and other family members with whom to interact. The subsidy provides financial support to families who have children with severe handicaps. It currently serves 2,700 families. The report provides results of an evaluation of the program. These results indicate that families have found the program helpful in meeting the special needs of their child and the family as a whole and that community mental health boards noted few problems in identifying eligible children. The program has been successful in averting some out-of-home placements and has been a factor in the return home of some children. For those children who have been placed out-of-home, the Department's policy of permanency planning is resulting in efforts toward reunification of families or the establishment of alternative permanent homes for children.

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TITLE: Respite care provider training: Current practices and directions for research

AUTHOR: Salisbury, C. L.

PUBLICATION INFORMATION: 1984

Education and Training of the Mentally Retarded, 19, 210-215

This article offers some valuable suggestions for meeting the training needs of respite care providers. It criticizes most existing approaches to training for failing to address the real needs as they are perceived by the people who are actually providing respite services. Nine elements are suggested as important in designing and implementing a field based training program which is responsive to the needs of service providers.

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TITLE: Support for caregiving families

AUTHORS: Singer, G. H. S. & Irvin, L. K. (Eds.)

PUBLICATION INFORMATION: 1989

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This edited book covers a broad range of issues related to supporting families. Chapters include discussions of family strengths, value-based services, coping skills, informal social support, and various kinds of formal support such as respite care, cash

assistance, early intervention, counseling, and many other formally arranged supports. The final chapters have to do with evaluation and policy development. This is one of the best published books on support for families.

TITLE: Site visit report: State of Michigan

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1985

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $2.75 plus 10% postage and handling

This report discusses Michigan's policy to return children from institutions to the community, and describes the state's Family Subsidy Act, its movement toward greater local control over services, and its family support/respite program. Appendices include the Family Subsidy Act legislation, the state's Mental Health Code, and a description of specific respite supports available to families.

TITLE: Family Support Bulletin

AUTHOR: United Cerebral Palsy Associations

PUBLICATION INFORMATION:

UCPA Governmental Activities Office
1522 K Street N.W., Suite 1112
Washington, DC 20005

COST: no charge

The Family Support Bulletin published its first issue in Summer 1987. Its threefold purpose is: (1) to be a source of information, research, policy and practice regarding supports for families having children with severe disabilities; (2) to solicit comments, articles, successes, and failures in family support services; and (3) to develop a national network of people committed to assuring the development of consistent policies in the private and public sector supporting families.

TITLE: Family supports for children with severe disabilities and chronic illnesses in Maryland

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1988

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $2.10 plus 10% postage and handling

This article describes some innovative family supports in the state of Maryland. Taking a "family-centered" approach to supports, the programs highlighted in this paper are able to provide some very individualized and flexible supports to children and their families, including some children with severe and multiple disabilities as well as chronic illnesses. Case examples within the report illustrate some of the different types of supports given to different families. Two additional strengths of the programs described in this report are: (1) they seek to take a role of "service coordination" for families rather than traditional case management; and (2) a primary emphasis of their assistance to families is one of advocacy and empowerment of the family.

TITLE: Family support program: Guidelines and procedures

AUTHOR: Wisconsin Department of Health and Social Services

PUBLICATION INFORMATION: 1985

Wisconsin Department of Health and Social Services
One West Wilson Street
P.O. Box 7851
Madison, WI 53707

This report gives a detailed description of Wisconsin's family support program. including: an overview (purpose, available services, etc.) of the program; the development of individualized family service plans; and administration of the program. Appendices include family support legislation, as well as samples of various program forms (i.e., family questionnaire, application for services, etc.).

PERMANENCY PLANNING

The materials in this subsection discuss the concept of permanency planning for children with developmental disabilities, from the point of view that all children need a permanent family. Permanency planning strategies include a "whatever it takes" approach to family support, family reunification efforts, and adoption or permanent foster care for children who cannot return to live with their birth families.

TITLE: Parents for children, children for parents: The adoption alternative

AUTHOR: Glidden, L. M.

PUBLICATION INFORMATION: 1989

American Association on Mental Retardation
1719 Kalorama Road, NW
Washington, DC 20009

This book is based on interviews with families into which children with developmental disabilities have been adopted and with agency workers responsible for arranging such adoptions. The book is organized to follow the steps in the birth and adoption process, giving many facts and statistics in each chapter. This is a good resource for agencies thinking about providing for adoption for children with disabilities.

TITLE: Dissemination and utilization of permanency planning strategies for children in foster care

AUTHOR: Lahti, J., Emlen, A., & Troychak, M.

PUBLICATION INFORMATION: 1981

In Children and Youth Services Review, Vol. 3, pp. 357-372. Pergamon Press, Ltd.

Request for reprints may be addressed to Janet Lahti, Regional Research Institute for Human Services, Portland State University, P.O. Box 751, Portland, OR 97207

This article provides a short description of the Permanency Planning Project, a national effort to disseminate and ensure utilization of strategies designed to reduce

"foster care drift" and place foster children in permanent families. Most of the article concentrates on the dissemination itself and is thus likely to be of interest to state-level developmental disability offices interested in moving toward permanency planning for children in developmental disabilities services. Many of these children have remained untouched by the permanency planning mandate for children served by state social services departments under the Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272), an act that resulted from the national push toward permanency planning, and have received attention only recently as children who often grow up without experiencing the benefits of permanent family homes.

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TITLE: Permanency planning practice for children with developmental disabilities within the Michigan mental health system: A manual for trainers

AUTHOR: Michigan Department of Mental Health in cooperation with Spaulding for Children

PUBLICATION INFORMATION: 1987

Community Services
Michigan Department of Mental Health
Lewis Cass Building
Lansing, MI 48926
(517) 373-3900

This training manual is designed to build commitment by staff of mental health and developmental disabilities agencies to the philosophy of permanency for children with developmental disabilities. This philosophy includes a commitment to maintaining children in families, whether birth or alternative families, in order that the child may have permanent ties and relationships. The manual is divided into ten units, with each unit serving as the basis for a training session of one-half to one day in length. The units include: 1) Preparing to train; 2) Gaining administrative and managerial support; 3) Permanency planning: What? Why? How?; 4) The bonding experience; 5) Aggressive, decisive casemanagement; 6) Developmental assessment and preparation; 7) Family assessment in the mental health system; 8) Preservation and reunification practice; 9) Adoption of children with developmental disabilities; 10) Lifespan advocacy. This is an excellent resource for anyone interested in children.

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TITLE: Site visit report: Macomb-Oakland Regional Center, Michigan

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1985

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $2.30 plus 10% postage and handling

Pages 15-24 of this report focus on Macomb-Oakland's specialized foster care program and permanency planning. The success of the Macomb-Oakland foster care program can be attributed to a number of factors: (1) making foster home recruitment an agency priority; (2) relatively good pay for foster families; (3) aggressive recruitment strategies (ads, public service announcements, radio and television appearances, posters, flyers, etc.); and (4) providing a lot of support to foster families (respite, professional consultation, home aides, special equipment and supplies, in-home modifications, etc.). The concept of permanency planning has also become a priority in the Macomb-Oakland region. This involves: (1) support of natural families; (2) when a child cannot stay at home, arrange for temporary foster care placement and plan for reunification with the natural family; (3) reunite the family or pursue other alternatives (such as shared care, permanent foster care, open adoption).

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TITLE: Permanency planning for children and youth: Out-of-home placement decisions

AUTHOR: Taylor, S. J., Lakin, K. C., & Hill, B. K.

PUBLICATION INFORMATION: 1989

<u>Exceptional Children</u>, <u>55</u>(6), 541-549.

This paper advocates the extension of the basic protections of "permanency planning" to all children and youth, including those with severe handicaps. It discusses the concept and process of permanency planning and notes its promise in improving the opportunities of all children and youth to grow up in a stable family environment. It demonstrates the need for major initiatives in this area by providing statistics on the number of children and youth with mental retardation in long-term care settings without such protections. It describes current programs operating according to the principles and procedures of permanency planning. It recommends significant changes in existing federal policy to require permanency planning as part of all considerations of federally supported out-of-home care for all children, including those with severe disabilities.

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COMMUNITY LIVING FOR ADULTS

The emerging approach to "community living" for adults with disabilities may be called an "individualized," "person-centered" or "housing/support strategy" approach. Essentially, this approach looks at housing and support as basic needs that people have. This approach reflects the tradition of packing housing and support together along a continuum of residential services. The most important part of a housing/support approach is to start with the person and his or her preferences for how, where, and with whom he or she would like to live. This means a person would (1) have individually tailored and flexible supports available wherever he or she chooses to live; (2) have the option to rent or own his or her own home; and (3) have choices in all aspects of life from major decisions, such as the location of the home, to more minor decisions such as scheduling staff time. This approach to housing and support services, of course, needs to be embedded in the broader context of community, family, relationships, etc. For resources in this area, please see the other bibliography sections, such as those in the "Beyond Paid Services and Supports" division of this bibliography and those in the "Planning with Individuals" section.

The three subsections below contain materials that discuss housing and support separately as well as together.

HOUSING

The resources in this section deal with a variety of creative options that can be used to purchase or subsidize rents for ordinary (rather than segregated or specialized) housing in the community, including apartments, houses, condominiums, housing cooperatives. The subsection includes some information on adapting or building housing to meet the needs of people with physical disabilities.

TITLE: A survey of housing trust funds

and

A guide to developing a housing trust fund

AUTHOR: Center for Community Change

PUBLICATION INFORMATION: 1989, January

Center for Community Change
1000 Wisconsin Avenue, N.W.
Washington, DC 20007
(202-342-0519)

The first of these two 100-page manuals offers an overview of housing trust funds describing how they work, what they have done, where they exist, and who to contact for further information. It also includes profiles of housing trusts in 34 states. The second book presents a guide to developing housing trust funds. Here the reader is given an overview, principles for developing housing trust funds, different models of administration, revenue sources and information on program issues (e.g., eligibility). Both books provide a bibliography for further reference.

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TITLE: Cooperative housing: People helping each other

AUTHOR: Cooperative Housing Foundation and National Association of Housing Cooperatives

PUBLICATION INFORMATION:

Cooperative Housing Foundation
1010 Wayne Avenue, Suite 240
Silver Spring, MD 20910

National Association of Housing Cooperatives
1612 King Street
Alexandria, VA 22314

Cooperative housing is a short book offering the reader basic information on housing cooperatives, including a brief history of their development, information on who might be interested in living in a coop, how a coop is structured and how to get started. The finances of coop establishment are presented including members' costs and issues in start-up. Finally, the book offers a comparison of rental, individual ownership and cooperative living, including such areas as ownership, community control, management, and tax benefits.

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TITLE: Social change through integrated housing

AUTHOR: Falta, P., & Cayouette, G.

PUBLICATION INFORMATION: 1978

ERIC Document 155 878

Described is Project Normalization, a three-year demonstration project funded by the Canadian government to develop appropriate housing and supportive community services for severely physically disabled adults. Reviewed are the project's short term efforts to arrange for housing adaptation and community resources, as well as long term goals of policy changes ensuring integrated housing systems. Among other activities said to promote the integrated housing concept throughout Quebec and Canada are the establishment of a nonprofit corporation for housing, and the convening of a conference on accommodations and services. Also reported are results of a follow-up study of 23 severely disabled people in integrated housing.

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TITLE: A guideline for developing a community trust program

AUTHOR: Field, P.

PUBLICATION INFORMATION: 1982

The Virginia Beach Trust Fund Program
for Developmentally Disabled People and Their Families
Pembroke Six, Suite 218
Virginia Beach, VA 23462

This 23-page outline lists the specific steps one organization took in establishing a community trust fund. It would be most useful to staff who are responsible for developing and implementing such a program. This information packet also includes a sample of a master trust agreement, instrument of adoption, exempt trust fund, beneficiary information review form, and organizational flow charts. Newspaper articles, a program brochure, and a list of trust and service programs are also provided.

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TITLE: Building partnerships

AUTHOR: Housing Technical Assistance Project

PUBLICATION INFORMATION:

Housing Technical Assistance Project
Association for Retarded Citizens
1522 K Street, N.W. Suite 516
Washington, DC 20005
202-785-3388

NAHB/National Research Center
400 Prince George's Boulevard
Upper Marlboro, MD 20772
301-249-4000

This monthly newsletter was developed and distributed by the Housing Technical Assistance Project (HTAP) in collaboration with the National Association of Home Builders (NAHB) and the National Association for Retarded Citizens (NARC). The newsletter provides technical assistance in the finance and design of affordable and accessible housing for people with disabilities.

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TITLE: Working with non-profit developers of affordable housing to provide integrated housing options for people with disabilities

AUTHOR: Housing Technical Assistance Project

PUBLICATION INFORMATION: 1989

Housing Technical Assistance Project (HTAP)
Association for Retarded Citizens
1522 K Street. N.W., Suite 516
Washington, DC 20005
202-785-3388

NAHB/National Research Center
400 Prince George's Boulevard
Upper Marlboro, MD 20772
301-249-4000

This is a case study of the Reservoir Cooperative. Madison Mutual Housing Association in Madison, Wisconsin. In addition to describing the advantages and disadvantages of this model, the paper provides information on different structures for cooperatives and alternative financing sources for cooperatives, including mortgage insurance. national cooperative boards, the Federal National Mortgage Association (FNMA) secondary market for cooperative blanket and share loans, state and local government agencies, tax exempt bonds, home ownership assistance programs, equity financing, low income tax credits, foundation and religious organizations, local initiative support corporation (LISC) and enterprise foundations.

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TITLE: Volume I. The development process
Volume II. The financing mechanisms

AUTHOR: Housing Technical Assistance Project

PUBLICATION INFORMATION:

Housing Technical Assistance Project (HTAP)
Association for Retarded Citizens
1522 K Street, N.W. Suite 516
Washington, DC 20005
202-785-3388

NAHB/National Research Center
400 Prince George's Boulevard
Upper Marlboro, MD 20772
301-249-4000

These two organizations are in the final stages of completing a two-volume document which offers a financing strategies guide for looking at housing alternatives that can be pursued for people with disabilities.

Volume I, The development process, provides an organizational structure that can be used by a group or individual as they first attempt to determine housing needs and the availability of housing in their community. The volume begins with some pointers on how to conduct a housing needs assessment, and how to establish links among advocacy organizations, consumers and the private sector, governmental agencies, and the community as a whole. These include ideas about identifying target populations, determining needs, looking at housing availability, determining how unmet needs can be addressed, and assessing the potential for community integration. The volume also describes the types of real estate investments useful in looking at different housing alternatives and the pros/cons for each.

Volume II, The financing mechanisms, offers detailed summaries of major financing mechanisms on the federal, state and private levels that can be used to develop affordable housing for people with disabilities. Programs offered through HUD, and state initiatives such as housing trust funds and mortgage insurance, are described along with where information on each can be obtained.

The project has also produced small individual packets on organizations in different states that have used these methods to provide affordable and integrated housing for people with disabilities.

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TITLE: The community land trust: A new system of land tenure

AUTHOR: Institute for Community Economics

PUBLICATION INFORMATION: 1986, June

Institute for Community Economics
151 Montague City Road
Greenfield, MA 01301
413-774-7956

This paper presents an overview not only of what a land trust is but the principles that direct community land trusts. The problem of how we use our land today is defined followed by a CLT approach to dealing with these problems. The

article takes the reader through a brief description of how the CLT works and describes advantages of such an approach.

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TITLE: People caring about people: The Prairie Housing Cooperative

AUTHOR: Kappel, B., & Wetherow, D.

PUBLICATION INFORMATION: 1986

Entourage, 1(4), Autumn 1986.

This article describes the Prairie Housing Cooperative which owns an eight-story apartment building with approximately 30 apartments as well as several clusters of homes across the City of Winnipeg. The cooperative includes a small number of people with disabilities living with non-disabled people. Locations were chosen close to other family members, employment opportunities, church connections and friends. In each of the five neighborhoods, the cooperative purchased clusters of two to four neighboring houses or apartment units with no more than two people with disabilities living in a home.

The Prairie Housing Cooperative has restricted itself to providing housing and supports for members with mental handicaps. Since all coops in Canada have a designated purpose (i.e., low income, young families), housing is separated from paid services to insure the service relationship does not affect the security of the person's housing.

The cooperative was developed in response to one man's need to leave the institution. A group of people got together and arranged for housing and support for him, which over time resulted in the cooperative. Funding was procured from the Canadian Housing and Mortgages Corporation (CHMC) through its social housing program (which subsidizes mortgages for coop homes by providing low interest loans). The Manitoba Department of Cooperative Development helped establish the structure of the cooperative and the regional office of CHMC helped purchase the first 18 units.

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TITLE: Publications list

AUTHOR: National Association of Housing Cooperatives

PUBLICATION INFORMATION:

National Association of Housing Cooperatives
1614 King Street
Alexandria, VA 22314
703-549-5201

This organization offers a publications list that covers every area of cooperative development, ranging from general information in various media, the structure and workings of the Board of Directors, cooperative membership, operating and maintaining housing cooperatives, developing cooperatives, samples of coop documents and forms, and other housing reference materials.

TITLE: Shelterforce

AUTHOR: National Housing Institute

PUBLICATION INFORMATION:

National Housing Institute
439 Main
Orange, NJ 07050

This is a bi-monthly publication of the National Housing Institute which serves a network of housing advocates and professionals with information about affordable housing strategies, industry issues, and workshops and events taking place in the area of housing. Other purposes of the publication are to build a national network of tenant and housing groups, to provide resources and information on the creation and preservation of decent, affordable housing for all, and to promote neighborhood development in the promotion of housing options.

TITLE: New directions in housing for people with severe disabilities: A collection of resource materials

AUTHOR: O'Connor, S., & Racino, J.

PUBLICATION INFORMATION: 1989

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $2.70 plus 10% shipping and handling

This is an information package specifically designed for people who wish to explore a "housing/support services" strategy. It provides an introduction to housing strategies and resources that can be used to promote home ownership by parents and people with disabilities, to make housing more accessible, and to increase the development and use of small, integrated housing options. The package highlights the use of trusts for housing, the development of cooperatives and housing associations, housing subsidies, housing resources and organizations engaged in providing housing.

The package is designed as a bridge between the housing and disability fields, and has proved to be very useful in that regard.

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TITLE: Introduction to cooperative housing

AUTHOR: Page, S.

PUBLICATION INFORMATION:

The Cooperative Initiatives Project
Page Associates
236 Gulf Road
Belchertown, MA 01007
(413) 253-3118
(203) 523-0890

This article is a brief and easy introduction to understanding cooperative housing in the United States in which the advantages and elements of coop involvement are discussed. The article points out the potential that coop members have to build a strong sense of community and support. In contrast to individual home owners, coop members are provided with many security and equity benefits. While functioning as a business corporation, coops are operated for the benefit of owner and resident. Each owner has voting privileges. The whole concept of the coop is based on involvement of the members. Though there is an elected board to manage day-to-day operations, membership involvement is highly encouraged and training programs are offered to members regularly.

The reader is provided a range of information about ways to establish cooperative housing, such as constructing new buildings, rehabilitating and purchasing existing structures, or leasing a building and having the cooperative manage that building. Examples of both coops and funding possibilities in places such as Connecticut, Massachusetts and Wisconsin offer the reader some concrete examples of how such projects have managed to find success.

Also addressed is the creation of mutual housing associations, which ensure that the return on capital investment of original projects is used to develop future housing options and provide long-term stability. This is another avenue that has been taken by groups of people, organizations and governmental bodies interested in housing development for low and moderate income people or to develop long term management support services to several independent coops. This article clarifies basic questions about establishing cooperatives as well as pointing out their many benefits.

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TITLE: Financing strategies for cooperatives

AUTHOR: Randolph, F., Laux, B., & Carling, P.

PUBLICATION INFORMATION: 1987

In F. Randolph, B. Laux, & P. Carling, In search of housing: Creative approaches to financing.

Center for Community Change Through
Housing and Support
University of Vermont
John Dewey Hall
Burlington, VT 05405
(802) 656-0000

This chapter explains how housing coops are developed under corporate laws of a state rather than real estate laws. In order to establish such a corporate body, articles of incorporation, by-laws, and occupancy agreements must be filed.

Tenant members collectively own and manage the cooperative. The article points out that the nature of a cooperative requires collective decision making and offers natural opportunities for interaction, integration and acceptance. The aspect of permanency is also a factor offering opportunities for joint ownership, decision making and operation.

The chapter explains the financing options that are available for housing cooperatives such as: Housing and Urban Development (HUD) which provides federal mortgage insurance under Section 213 and Farmers' Home Administration (FmHA) which provides cooperative construction and mortgage loans under rural cooperative housing programs. State agencies can be a source of funding if they choose to re-program capital funds which in the past were used to build community facilities or renovate institutions.

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TITLE: In search of housing: Creative approaches to financing integrated housing

AUTHOR: Randolph, F., Laux, R., & Carling, P.

PUBLICATION INFORMATION: 1987

Center for Community Change Through
Housing and Support
University of Vermont
John Dewey Hall
Burlington, VT 05405
802-656-0000

This monograph outlines and identifies effective resources in relation to housing opportunities for people with labels of mental illness. It highlights the economics of housing, offers more specific insight into understanding real estate language, and discusses private investor ownership and financing strategies for consumer and family ownership. An overview of government programs which finance housing on a federal, state and local level is included. Finally, it addresses issues of implementation of integrated housing offering a six step process of what should be looked at in such a

pursuit. The reader is provided with a list of references and a bibliography. Though the text focuses on the mental health system, it offers a great deal of useful information applicable for people and agencies desiring to understand integrated housing for other individuals.

TITLE: Affordable housing: The American Day Dream

AUTHOR: Rosen, D.

PUBLICATION INFORMATION: 1988

Business and Society Review, No. 67, Fall 1988.

The article discusses the need for a national housing trust that can provide a "predictable, adequate revenue source needed to sustain an affordable housing production and preservation." Rosen argues that in combination with a coherent national housing policy and existing federal, state, local and private sector investment, a national housing trust could help meet the nation's needs for low and moderate income housing. This idea of a large scale, affordable housing program of new construction, rehabilitation and preservation that is self-financing and permanently endowed may be a piece of what will regenerate housing in America.

Rosen discusses how trust funds have been used in the past in the Social Security Trust Fund, National Highway Trust Fund, and Airport Safety Trust Fund. All were created nationally in response to strong needs and capitalized by self-financing. The nature of the housing crisis in this county, Rosen claims, requires such large scale commitment. Seventeen states and numerous localities have already enacted such programs.

TITLE: The do-able renewable home: Making your home fit your needs

AUTHOR: Salmen, J. P. S.

PUBLICATION INFORMATION: 1985

American Association of Retired Persons
Washington, DC

This readable and well-illustrated monograph presents a range of modifications that would make a typical house more physically accessible. Chapters cover the major household spaces with specific attention paid to bathrooms, kitchens, and stairs. Designed for older individuals who are experiencing some loss of physical function, this monograph is useful for home designers who wish to build in and/or increase the adaptability of a house.

TITLE: New housing policy for America: Recapturing the American dream

AUTHOR: Schwartz, D. C., Ferlauto, R. C., & Hoffman, D. N.

PUBLICATION INFORMATION: 1988

Temple University Press
Philadelphia, PA 19122

This book examines what the 1980s has brought to the area of housing in terms of a decline in home ownership, increase in homelessness and decrease in affordable and available rental units, and discusses what challenges will be faced in the 1990s.

In the 1990s, most analysts agree that at least four demographic trends are likely to pose challenges to housing policies: (1) the huge increase in the number of people 75 years and older; (2) the sharp upturn in the number of single people living alone and single parent female headed households; (3) the increase in young families in early years of home buying; and (4) the larger concentration of poor families.

The number of very low income Americans is expected to increase by almost 6 million by the 1990s and experts fear that, by the year 2000, one third of all Americans and 70% of the poor will confront inadequate and unaffordable housing. The book discusses state programs in the 1980s which must be considered in national housing policy yet these alone cannot meet the housing needs that exist and will continue to arise.

The book offers a good overview of the housing issues related to policies, but is not creative in generating solutions for the elderly and people with disabilities. It includes a variety of options presently being used such as group homes. They do talk, however, about shared housing and staying with family and friends and look at some programs as being untapped (e.g., ECHO, a model from Australia which has small houses around a central area). It offers a very good overview of the housing situation in America today.

TITLE: Attorney handbook: Estate planning for persons with disabilities

AUTHOR: Sheen, T. M.

PUBLICATION INFORMATION: 1988

Illinois Self-Sufficiency Trust
340 West Butterfield Road
Elmhurst, IL 60126
(312) 832-9700

This is one of the resources in an excellent information package available from the Illinois Self-Sufficiency Trust (SST) and produced in conjunction with the National

Foundation for the Handicapped. The manual includes highlights of Illinois state law, detailed information on the SST including its relationship to other federal funds such as Medicaid and SSI, taxes, trust participation and services. In addition, the appendix includes sample documents.

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TITLE: What should I know about residential services

AUTHOR: Turnbull, H. R., Turnbull, A. P., Bronicki, G. J., Summers, J. A., & Gordon-Roeder, C.

PUBLICATION INFORMATION: 1989

In H. R. Turnbull, A. P. Turnbull, G. J. Bronicki, J. A. Summers, & C. Gordon-Roeder (Eds.), Disability and the family: A guide to decisions for adulthood. Baltimore, MD: Paul H. Brookes.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This chapter is included here because it is written specifically for families and includes a section on consumer and family home ownership. It discusses types of creative financing that can be used, and emphasizes the importance of careful and detailed planning. It also offers a case example of how one family created the ability for their son to own his own home.

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TITLE: Community sponsorship of housing cooperatives

AUTHOR: Wilcox, R.

PUBLICATION INFORMATION: 1987

National Association of Housing Cooperatives
1614 King Street
Alexandria, VA 22314
(703) 529-5201

This booklet discusses advantages and disadvantages of housing cooperatives, what community sponsors can expect from a cooperative, types of housing cooperatives in the United States, and information on how to start a cooperative. The booklet also discusses mutual housing associations (MHA) which are not used extensively in the United States, but may be in the future.

A MHA is housing produced, owned and operated by a not-for-profit, public interest organization where those who develop the housing and those who will live in it join together in membership. The MHA is the umbrella organization that then can

sponsor single and multifamily non-profit cooperatives, condominiums and rental housing. The booklet is brief and offers a good overview of some basic questions related to housing cooperatives.

SUPPORT SERVICES

The resources in this subsection discuss a variety (not exhaustive by any means) of supports and services that have been used by people with disabilities so that they could live in homes of their own. We ask the reader to remember that supports must be individually tailored, that a variety of supports may be required, and that the kinds and intensity of support are likely to change over time. We also ask the reader to consider that people should have choices about who they live with, and that their choices should not affect the support they receive. Thus, a person might want to remain with his or her family, get married, live with roommates, or live alone. Although there is a relatively heavy emphasis in this section on personal assistance services, there are many other supports needed by people with developmental disabilities. It should also be evident that the resources in this section emphasize formal (i.e., paid/contracted for) support services. The "Beyond Paid Services and Supports" division includes many other supports people need to live full lives in the community.

TITLE: Independent living with attendant care

1. A guide for the person with a disability
2. A guide for the personal care attendant
3. A message to parents of handicapped youth

AUTHOR: Board, M. A., Cole, J. A., Frieden, L., & Sperry, J. C.

PUBLICATION INFORMATION: 1980

Independent Living Research Utilization (ILRU)
The Institute for Rehabilitation and Research
1333 Moursand Avenue
Houston, TX 77030

These booklets, although they are ten years old, are included because attendant care is increasingly being utilized is a form of support for people with severe disabilities.

A guide for the person with a disability includes a discussion on where to look for a personal care attendant, how to word an advertisement, what to discuss when interviewing, how to establish a satisfactory working relationship, what are reasons for terminating an attendant, and how to develop a back-up plan.

A guide for the personal care attendant addresses issues such as what independent living means and how attendant care supports it, good places to look for employment as an attendant, how to word a position wanted ad, issues that need to be clarified in interviewing, how to establish a satisfactory working relationship, and typical rewards to being a personal care attendant.

In A message to parents of handicapped youth, the issues discussed include what the independent living movement connotes for one's disabled child, how to teach responsibility to handicapped children, what support systems are necessary for living independently, which independent living situations require personal care attendants, and when to use attendants.

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TITLE: Self-directed attendant services: Toward a consumer oriented policy and perspective on personal support services

AUTHOR: Centre for Research and Education in Human Services

PUBLICATION INFORMATION: 1990

Centre for Research and Education in Human Services
P.O. Box 3036, Station C
Kitchener, ON N2G 4R5
CANADA

For U.S. readers, the most interesting parts of this monograph are its analysis of the difference between a health/welfare model and a rights/empowerment model for provision of personal support for people with physical disabilities, and the framework it presents for self-directed attendant services. The approach the monograph espouses is based on a qualitative study of consumers' wishes and desires, and is most applicable for people who do not need support to direct their own attendants. Many of the ideas proposed, however, could be adapted to meet the needs of people who do need such support--for example, a rights/empowerment approach rather than an approach that removes choice and control from the person.

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TITLE: Belonging to the community

AUTHOR: Johnson, T. Z.

PUBLICATION INFORMATION: 1985

Options in Community Living
22 North Second Street
Madison, WI 53704

This book is probably the best resource presently available for the residential provider concerned with providing supportive living services to people with severe

disabilities. It is made up of a series of six papers which describe Options in Community Living, a supported apartment program in Madison, Wisconsin.

The six sections of the manual include: 1) An overview of the Options program, with particular emphasis on the values which guide it and how it has changed over time; 2) A description of this agency's administrative structure, including the definitions of various administrators' roles, funding consideration, and consumer participation; 3) A review of Options' staff organization with clear descriptions of its team approach, various staff positions (including overviews of a typical day in the life of various staff members), and procedures for staff hiring, training, and evaluation; 4) An examination of the fundamental principles which guide this agency's service practice and a review of the processes used to plan, implement, and evaluate activities on behalf of each individual served by it; 5) A discussion of how an agency can aid someone's integration into the community with special attention given to major dilemmas, strategies, issues of relationship building, and advocacy for change in the community; and 6) An analysis of how services are adapted to meet the needs of "special populations," including people with physical disabilities, people with significant learning problems, and people with challenging behaviors. Each paper is supplemented with a variety of useful materials which rum the gamut from maps and budgets to job descriptions, assessment forms, and policy statements.

The entire manual is useful, but the final three sections provide instructive, thought provoking reading for anyone involved in supporting people with severe disabilities in the community. It is particularly refreshing to find a resource which directly recognizes the difficult issues of autonomy, choice, risk, and relationship building which emerge when an agency is truly committed to facilitating the integration of individuals into the community.

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TITLE: Carrying Options' story forward: Final report of an assessment of Options in Community Living

AUTHOR: Johnson, T., & O'Brien, J.

PUBLICATION INFORMATION: 1987

Options in Community Living, Inc.
22 North Second Street
Madison, WI 53704

An excellent supplement to the Options manual, this evaluation report focuses on the views of Options staff on a variety of topics, ranging from their descriptions of the people they serve to issues they see as pertinent to future development. The report also includes feedback by the evaluators on issues pertinent to the staff and of concern to most service providers, issues such as the amount of involvement staff have in people's lives and how to help people develop relationships with community members. Staff concerns regarding the amount of time they had to devote to assist in building relationships along with the inadequacies they felt in being responsible for "getting friends for people" are also presented. The report provides some constructive

ways in which staff might enhance the building of relationships, and describes Options' continued commitment in principle and action in supporting people with severe disabilities.

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TITLE: Beyond caregiving: A reconceptualization of the role of the residential service provider

AUTHOR: Knoll, J., & Ford, A.

PUBLICATION INFORMATION: 1987

In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities (pp. 129-146).

Teachers College Press
Columbia University
1234 Amsterdam Avenue
New York, NY 10027

This chapter is a relatively early conceptualization of the idea that providers should support individual people with severe disabilities in places and routines they prefer rather than provide programs to groups of people who often are forced to wait passively for something to be done to them. The authors assert that reconceptualizing their primary role as "facilitators" of home and community participation would help providers to resolve some of the tensions that seem to be inherent in providing residential services. They go on to describe several components of support--interdependence, facilitation, and helping a person make a home--and list principles and strategies for realizing them.

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TITLE: Attending to America: Personal assistance for independent living

AUTHOR: Litvak, S., Zukas, H., & Heuman, J. E.

PUBLICATION INFORMATION: 1987

World Institute on Disability
510 16th Street
Oakland, CA 94612

This booklet offers an excellent overview of personal attendant service to people of all ages who have disabilities. It provides information on the available funding mechanisms and a breakdown, by state, of different ways in which personal assistance is organized. This booklet is most useful to people who are interested in the many issues arising from attendant services and to people who are involved with Independent Living Centers and are considering coordination of attendant services.

This booklet is comprehensive in its examination of the many aspects of attendant services, including financial considerations; the independence of, and control by, the consumer; and the availability and quality of care. Tables illustrate the results of a national survey, the conclusions of which suggest the creation of a national personal assistance program. The authors list recommendations regarding the format of such a program.

TITLE: Personal assistance services for persons with mental disabilities

AUTHOR: Nosek, M. A.

PUBLICATION INFORMATION: 1990

Baylor College of Medicine
3400 Bissonnet, #101
Houston, TX 77005

This paper, prepared for the National Council on Disability, provides an excellent review of the developmental disabilities and mental health literature on personal assistance services, including both formal and informal support. The paper concludes that "the principle of individuals determining and maintaining a life style of their choice has emerged as a common thread across recent developments in all disability groups" (p. 8). It points out the challenge of changing the traditional service systems and funding mechanisms to allow this principle to be realized, and asks that policy makers develop policy strategies that will make this possible.

TITLE: Personal assistance services for people with disabilities

AUTHORS: Nosek, M. A., Potter, C. G., Quan, H., & Zhu, Y.

PUBLICATION INFORMATION: 1988

Baylor College of Medicine
3400 Bissonet, #101
Houston, TX 77005

Developmental disabilities services in many states are now looking at ways to incorporate the concept of personal assistance into their services, and are trying to learn how to use the actual services provided within their states on behalf of individuals with physical disabilities. This bibliography represents most of the current material on personal assistance services.

TITLE: Community living in three Wisconsin counties

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1986

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $3.25 plus 10% shipping and handling

This site visit report highlights the innovative practices in community living for people with severe disabilities in Dane, Lacrosse, and Columbia Counties including: (1) county leadership, (2) setting priorities for case management, (3) family support, (4) innovative community living arrangements, and (5) the community integration program medicaid waiver. The stress throughout on individualization and flexibility particularly makes this report worth reading.

TITLE: A step-by-step guide to training and managing personal attendants

Volume 1: Consumer guide
Volume 2: Agency guide

AUTHOR: Ulicny, G. R., Adler, A. B., et al.

PUBLICATION INFORMATION: 1987

Research and Training Center
on Independent Living (RTC/IL)
University of Kansas
Lawrence, KS 66045

These step-by-step instruction manuals are detailed guides for consumers and agencies who are exploring the usage and employment of personal care attendants (PCAs). These manuals begin with a discussion of pre-employment preparation. Practice interviews are encouraged and a thorough analysis of one's needs before beginning the recruitment process is stressed as a necessity. A look at matching applicant characteristics and personal needs and expectations follows. The manuals also contain detailed guides to assist consumers with providing appropriate feedback to their PCAs. Scheduling and emergency back-up networks are included topics.

Both of these manuals are styled in an easy-to-read and friendly format. The first manual is written for the consumer and was developed by a group of people experiencing disabilities. The second manual, which is an agency guide, focuses on

enabling the consumer to regulate the use of their PCAs, as much as possible, while providing back-up support to ensure that quality standards are being met. The agency manual is an addendum to the consumer guide.

HOUSING AND SUPPORT

The resources in this section discuss the issues of housing and support as separate issues, but both issues are discussed in each paper or article. As in the other sections, we include materials written about housing and support for people with a variety of disability labels.

TITLE: Major mental illness, housing and supports: The promise of community integration

AUTHOR: Carling, P. J.

PUBLICATION INFORMATION: 1989

American Psychologist, Fall 1989.

As in the field of developmental disabilities, mental health policymakers and consumers are increasingly discussing the importance of assisting people diagnosed as having major mental illnesses to obtain permanent housing and appropriate, flexible supports so that they can succeed in living in the community. This article describes the "supported housing" approach currently under implementation by mental health practitioners in several states. The author points out that traditional mental health approaches, including time-limited transitional residential programs, have not met the needs of the vast majority of people with severe psychiatric disabilities. He summarizes a recent review of the research on housing for all disability groups, which concludes that housing needs are similar for all the groups, while support needs are varied, and that supports are critical in achieving success; that consumers generally want normal housing, control over their environment, and choices about where and with whom they will live.

TITLE: Policy institute 1989: Community living for adults

AUTHOR: Center on Human Policy

PUBLICATION INFORMATION: 1989

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $2.10 plus 10% shipping and handling

This is a summary of a national institute held in 1989 to expand the critical thinking in the field about supporting adults with developmental disabilities in the community and to develop a statement to provide direction for the 1990s. Included in the summary are results of three working groups on home, personal assistance and community.

TITLE: Settling down: Creating personal supports for people who rely on the residential support program of Centennial Developmental Services

AUTHOR: O'Brien, J., & Lyle, C.

PUBLICATION INFORMATION: 1989

Decatur, GA: Responsive Systems Associates.

Available from:
Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

This is a report on one organization that began a process in 1985 of transforming the way that people with developmental disabilities live in Weld County, Colorado. In addition to describing the transformation process, this report highlights leadership, the dimensions of the relationship between staff and each individual they support, moving to a deeper understanding of choice for people with severe disabilities, changes in staff roles, among a myriad of other issues. (See Walker, P.: Report on Centennial Developmental Services, Weld County, Colorado. Syracuse: Center on Human Policy for an earlier description of this organization.)

TITLE: Preparing personnel to work in community support services

AUTHOR: Racino, J. A.

PUBLICATION INFORMATION: 1990

In A. Kaiser & C. McWhorter (Eds.), Preparing personnel to work with persons with severe disabilities (pp. 203-226). Baltimore: Paul H. Brookes.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This chapter describes changing directions in community living for people with developmental disabilities, including an emerging approach for adults which emphasizes home ownership, the separation of housing and support services, flexible and individualized supports, and consumer-directedness of services. In addition to describing what personnel need to know, the chapter describes emerging issues and directions for future personnel training, including the need to shift from teaching by service category to a focus on the individual lives of people.

TITLE: Moving into the 1990s: A policy analysis of community living for adults with developmental disabilities in South Dakota

AUTHOR: Racino, J. A., O'Connor, S., Shoultz, B., Taylor, S. J., & Walker, P.

PUBLICATION INFORMATION: 1989

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $8.00 plus 10% shipping and handling

This policy analysis describes specific issues and recommendations that South Dakota faces in moving to an "individualized," "person centered," or "housing/support" services approach to supporting adults in the community. Part II of the report examines five major aspects of this approach, including the separation of housing and supports, home ownership and housing, individualized and flexible supports, consumer directed services, and a close tie among the components of individual assessment, planning and funding. The report includes an examination of the roles of support staff and the importance of decision making by people with disabilities, among other issues.

TITLE: Supporting adults with severe disabilities in the community: Selected issues in residential services

AUTHOR: Racino, J. A., & Walker, P.

PUBLICATION INFORMATION: 1988

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $1.75 plus 10% shipping and handling

This article presents issues related to supporting adults with complex medical needs and other severely disabling conditions to live in the community. The article discusses the need to consider each person's housing separately from the supports needed to live in the home he or she has chosen, and then explores concepts like flexibility, individualization, and choice. The supports needed by people with complex medical or other challenging needs are examined, including backup systems, specifically trained staff, physical adaptations, and support for community participation.

TITLE: Coming home: Ex-patients view housing options and needs Proceedings of a national housing forum

AUTHOR: Ridgway, P. (Ed.)

PUBLICATION INFORMATION: 1988

Center for Community Change
Through Housing and Support
John Dewey Hall
University of Vermont
Burlington, VT 05405
(802) 656-0000

This paper is based on a forum which called together a small group of ex-patients of the mental health system to discuss housing and support. The participants agreed that people with psychiatric disabilities want and need typical community housing (e.g., apartments, houses, cooperatives, etc.) with consumer-controlled support. Instead, they are usually forced into group living situations or single room occupancy hotels where they experience lack of privacy, lack of control over their home, transience, stressful interpersonal relations, even danger, and regimentation. The group discusses consumer preferences in housing, attitudinal barriers within the mental health profession, and the types of supports that should be available to enable people

to live in the homes of their own choosing. This is an insightful piece that applies to any disability group.

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TITLE: Community living for adults: A newsbulletin

AUTHOR: Shoultz, B. (Ed.)

PUBLICATION INFORMATION: 1989

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $.85 for one copy (includes shipping)

This bulletin highlights promising practices, issues and resources for supporting adults in the community. A readable, concise newsletter-style document, it combines individual examples and conceptual articles to get at some of the how-tos for supporting people in homes they own, rent, or share with others.

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TITLE: Regenerating a community: The story of Residential Inc., New Lexington, Ohio

AUTHOR: Shoultz, B.

PUBLICATION INFORMATION: 1990

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $2.70 plus 10% shipping and handling

This is one in a series of over 40 case studies prepared by the Center on Human Policy on good practices of organizations in supporting people with severe developmental disabilities in the community. In addition to describing the story of people connected to this small agency in rural, Ohio, this case study highlights the changing relationship between staff members and the individuals they support, important aspects of the decision-making process and ways quality lives are promoted for each person.

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TITLE: Report on Centennial Developmental Services, Inc., Weld County, Colorado

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1987

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

This qualitative site visit report describes the individualized ways in which adults with disabilities are being supported in the community in this predominantly rural county. This report highlights a new way of thinking about supporting adults with severe disabilities (see O'Brien and Lyle: Settling down: Creating personal supports for people who rely on the residential support program of Centennial Developmental Services, annotated on page 82, for a later evaluation of this program. These can be read as companion pieces).

Two other policy analyses prepared by the Center on Human Policy discuss housing and support issues. These are:

TITLE: A policy analysis of the Supported Housing Demonstration Project, Pittsburgh, Pennsylvania

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1987

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $4.45 plus 10% shipping and handling

TITLE: A policy analysis of private community living arrangements in Connecticut

AUTHOR: Taylor, S. J., Racino, J. A., & Rothenberg, K.

PUBLICATION INFORMATION: 1988

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $5.20 plus 10% shipping and handling

EDUCATION IN THE REGULAR CLASSROOM

This is an exciting time to review materials on education for students with severe disabilities. The books and articles in this section, for the most part, reflect an approach which emphasizes functional curricula, community-based instruction, and full integration in regular classrooms in neighborhood schools. Several present issues for children in specific age groups (such as preschool or school-age) or having specific disabilities (such as autism or chronic illnesses). Others apply to students across a range of age groups or disabilities, or have separate chapters that look at these issues. The publications included in this section address school integration strategies and approaches, although not all support full integration in regular classes.

TITLE: Program models for mainstreaming: Integrating students with moderate to severe disabilities

AUTHOR: Berres. M. S., & Knoblock. P.

PUBLICATION INFORMATION: 1987

Aspen Publishers, Inc.
1600 Research Boulevard
Rockville, MD 20850

Generally speaking, the integration of students with moderate to severe disabilities has largely depended upon the attitudes and problem-solving skills of educators who often seem to believe that disabled students must prove they are ready to be integrated by attaining a certain level of skill. This book believes, instead, that all children with disabilities can be integrated, and attempts to alter the regressive attitudes still held about children with disabilities by presenting a number of credible examples of school districts that have undertaken the complicated task of providing integrated educational experiences for all their students.

An excellent collection of success stories that describe how educators in the field are working to implement the integration of children with moderate and severe

disabilities within their own school systems, it also includes discussions on the philosophical bases and the historical trends of development in special education. The concluding chapter summarizes the most significant characteristics of the programs that have contributed to their success--and the benefits enjoyed by all.

. . . . . .

TITLE: Achieving the complete school: Strategies for effective mainstreaming

AUTHOR: Biklen, D.

PUBLICATION INFORMATION: 1985

Teachers College Press
Columbia University
1234 Amsterdam Avenue
New York, NY 10027

This book clearly examines principles and strategies for use in achieving successful integration of students, including those with severe disabilities, into regular classrooms in neighborhood schools. Although there are separate chapters to address the particular role of several different groups--district special education administrator, school building principal, teacher, and parent--they emphasize and show that each group becomes "more effective when it understands the basic nature of the other groups' roles."

Co-authors of specific chapters include Robert Bogdan, Stanford J. Searl, Jr., Steven J. Taylor, and Dianne Ferguson. The areas examined include not only special education/regular education issues, such as principles for curriculum planning, but also the basic aspects of organization and change that make mainstreaming work. Numerous case examples illustrate the complexities involved in mainstreaming, the relationship of the process to the culture of schools, and the many critical issues affecting the integration of special and regular education. Based on the experiences of scores of administrators, teachers, and parents, the material in Achieving the complete school has been drawn from two extensive studies funded by the National Institute of Education and the U.S. Department of Education, and carried out simultaneously over three years.

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TITLE: Special education does not mean special classes: Two parents' observations about Louisville, Kentucky's experiences in integrating special and regular education systems and students

AUTHOR: Brost, M., & Johnson, T.

PUBLICATION INFORMATION: 1986

Wisconsin Coalition for Advocacy
16 North Carroll Street, Suite 400
Madison, WI 53703

Two parents of children with several substantial disabilities have written this informative monograph that provides observational, non-evaluative descriptions of five programs in Louisville, where children with significant disabilities are integrated into regular education classes. All the five programs are based on the valued educational goal that students with severe disabilities should be taught to function in a regular school environment, to interact appropriately with their non-handicapped age peers and to form friendships with some of those age peers. Yet, systemic or administrative and individual innovations have contributed to the development of five very different examples of restructuring existing funding sources and arranging physical space and staff time to support integration. The monograph gives detailed descriptions of each program, and points out the advantages, disadvantages and general issues raised by each approach.

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TITLE: Towards the realization of the least restrictive educational environments for severely handicapped students

AUTHOR: Brown, L., Wilcox, B., Sontag, E., Vincent, B., Dodd, N., & Gruenewald, L.

PUBLICATION INFORMATION: 1977

Journal of The Association for the Severely Handicapped, 2(4), 195-201.

The authors argue that least restrictive environment means desegregation. The basic argument is that service delivery models for the severely handicapped should closely approximate the best models used for non-handicapped students. There are a number of dimensions in an integrated education for the severely handicapped: (1) educational experience should be representative and prepare the severely handicapped to function in an integrated environment; (2) the ratio between severely handicapped and nonhandicapped students should represent less than 2% of the population at any chronological age; (3) there should be chronological age appropriate educational environments; (4) environments and architecture should be adapted; (5) there should be a functional curriculum; (6) the organization of the school day should approximate that of nonhandicapped peers; (7) there should be equal access to school facilities and resources; (8) transportation time should approximate time and type used by nonhandicapped peers; (9) necessary supportive services should be available.

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TITLE: Public school integration of severely handicapped students: Rational issues and progressive alternatives

AUTHOR: Certo, N., Haring, N., & York, R. (Eds.)

PUBLICATION INFORMATION: 1984

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

As part of the literature on integration for severely disabled students, this book moves beyond the almost repetitive debate of integration/segregation: It makes an important contribution by illuminating and extending our understanding of the topic of integrating learners with severe disablities. It enriches our knowledge of how schools can foster integration by describing basic principles around which curricula and administrative practices can be designed.

The specific chapters examine: the issues and alternatives for statewide integration, the complex nature of real integration, parent perspectives on obtaining integrated services, school administrative policies which foster integration, how to develop shared goals, principles and instruments for measuring a school's resolve for integration, teacher preparation and integration, and the meaning of integration. In addition, five chapters provide guidelines for developing curricula which are geared to facilitating integration in the areas of social performance, peer interaction, social behavior, interpersonal interactions, and recreation and leisure.

TITLE: Community-based curriculum: Instructional strategies for students with severe handicaps

AUTHOR: Falvey, M. A.

PUBLICATION INFORMATION: 1986

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

There are two reasons to recommend this book. One is the explicit intent of the author to provide general parameters and strategies for developing a community-based curriculum as opposed to using a "formula" or "recipe" approach that does not meet individual needs. The other is that, despite the fact that the book is organized by chapters according to domains or skill areas, like communication, academic skills, recreation and leisure, the author has made every effort to make connections across domains to describe a comprehensive and inter-related curriculum. The chapter on functional academic skills is the best example of this effort.

The book describes job skills inventories and discrepancy analysis, augmentative and alternative communication approaches, age-appropriate recreation and leisure skills that involve choice-making, and gives checklists of questions to establish priorities among skill areas. It examines the issues of volunteering or unpaid meaningful work as an occupational option, integrated therapy, community access, and family involvement. There is an emphasis on the use of ecological and student repertoire inventories, and the use of non-aversive applied behavioral analysis that incorporates generalizability of taught skills.

The author's stand on integration is cautious and restricted to integration within regular schools. The strategies described, however, include peer tutoring, the special friends project and project reach, which are equally applicable to regular classroom situations as well.

TITLE: Curriculum decision making for students with severe handicaps: Policy and practice

AUTHOR: Ferguson, D. L.

PUBLICATION INFORMATION: 1987

Teachers College Press
Columbia University
1234 Amsterdam Ave
New York, NY 10027

All too often, curricular goals like functional/community-based instruction, competitive work, and participation in community domestic and recreational activities have been dismissed as being unfeasible options for students with severe disabilities. By taking as data the meaning of curriculum to teachers, this fascinating and thought-provoking book analyses the implications of these curricular goals for students with severe disabilities and looks at how secondary school teachers have translated and implemented these goals in their own classrooms.

The author concludes that, while new public policy mandating education for severely handicapped students has generated substantial changes, both systemic and individual, the reform has not been extensive enough to overthrow prevalent standards of productivity that measure human worth in terms of earning capacity. Thus, although many severely handicapped students increasingly participate in heterogeneous communities, too many do not and will not. It is the author's contention that teachers contribute to this failure by assuming its inevitability and denying their students the opportunity even to fail.

TITLE: More education/integration: A further collection of readings on the integration of children with mental handicaps into regular school systems

AUTHOR: Forest, M. (Ed.)

PUBLICATION INFORMATION: 1987

The G. Allan Roeher Institute
Kinsmen Building, York University Campus
4700 Keele Street
Downsview, ON M3J 1P3
CANADA

This delightful collection of readings challenges the prevalent model of a cascade of services that locks special children into special, that is segregated, environments by offering a new and exciting alternative concept: the kaleidoscope. This apt metaphor is used to describe the pattern that emerges when the different "bits and pieces" of a community are put together to make a complete picture: all children, including children with challenging educational needs, going to their neighborhood schools in ordinary classrooms with other children their own age.

The readings provide philosophical, professional, and practical ways in which integration should and can be done. The MAPS Action Planning System, a systems approach to help professional team members, with student participation, plan for the integration of students with challenging needs into regular age-appropriate classrooms, is outlined. Programs that have successfully integrated students are described, programs that required commitment from regular classroom teachers, principals and superintendents, special education personnel, school boards, parents and students. But most of all, this is a book of stories. Stories about people, some with disabilities, some without, but all people first.

TITLE: Topics in Early Childhood Special Education: Chronically Ill Children, (Volume 5, Number 4)

AUTHOR: Garwood, S. G. (Ed.)

PUBLICATION INFORMATION: 1986

Pro-ED
5342 Industrial Oaks Boulevard
Austin, TX 78735

The nine articles in this special issue of TECSE cover a wide range of issues in services for children with chronic illness. The unifying thread of the articles seems to be an effort to sensitize professionals--especially educators--to the major concerns in this field. The lead article describes why the issue of children with chronic illness

is one which merits attention. The following pieces deal with early childhood education programs, special developmental issues, parents' perspectives, research issues, fiscal concerns, professional communication, professional and organizational attitudes, and educational resources as they relate to children with chronic illness.

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TITLE: Integration strategies for students with handicaps

AUTHOR: Gaylord-Ross, R. (Ed.)

PUBLICATION INFORMATION: 1989

Paul H. Brookes
P.O. Box 10624
Baltimore, MD 21285-0624

Written as an introductory textbook for regular and special educators in training, this book represents a commitment to progressive inclusion for students with handicaps. The book is divided into three main sections: (1) the education of students with different types of disabilities; (2) innovative techniques in integration; and (3) the ecology of delivering services to persons with disabilities. Each chapter provides practical information, with actual teaching techniques in real situations being put forth. Not only is this book helpful for teachers, school administrators, school psychologists, and parents would also benefit from it as well.

While the strategies for specific disabilities are helpful, it is important for the reader to recognize the fact that each student is an individual first, and that there are no prescribed techniques for specific disabilities. It would be erroneous for the reader to conclude that this is a "cookbook" for integration and disability. The innovative techniques for integration span a wide spectrum of options, and provide the reader with some interesting ideas.

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TITLE: Implementing a community-based educational model for moderately/severely handicapped students: Common problems and suggested solutions

AUTHOR: Hamre-Nietupski, S., Nietupski, J., Bates, P., & Maurer, S.

PUBLICATION INFORMATION: 1982

Journal of The Association for the Severely Handicapped,
7(4), 38-43.

A common administrative reaction to proposals to adopt a community based training model for severely handicapped students is that, while this is a good idea on paper, the relative difficulties of implementing such a model prohibit school districts from adopting it. This article outlines six commonly cited barriers to

community-based instruction: 1) limited staff, 2)transportation, 3) scheduling, 4) cost, 5) negative reaction to curriculum emphasis change, and 6) applicability to multiply handicapped students. For each of these common objections the authors offer a number of solutions drawn from the experience of implementing a community-based instructional model in 10 school districts in the State of Iowa.

TITLE: Education of learners with severe handicaps: Exemplary services strategies

AUTHOR: Horner, R. H., Meyer, L. H., & Fredericks, H. D. B. (Eds.)

PUBLICATION INFORMATION: 1986

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

Here is empirical evidence that the principles of normalization and integration do work for people with severe disabilities. This "must read" book is directed toward those teachers, administrators, parents, and service providers who accept the values of normalization and integration necessary for effective education, and are looking for a technology that is consistent with these values. Its focus is on new and innovative service strategies that are effective and reflect prevailing beliefs that educational objectives should be age appropriate, community referenced, and designed for maximal participation in integrated environments.

The first section of the book describes service delivery strategies, including vocational programming for adults in urban and rural environments, the use of advanced technology to meet the needs of young children with severe handicaps, and a family systems theory approach for individualizing parent involvement in education. The second section addresses recent advances in curriculum development for social skills, communication, and integrated instruction. Procedures for building functional social and communication skills, and the Individualized Curriculum Sequencing Model that sequences instruction around "skill clusters" rather than conventional massed practice of isolated skills, are described. The last section addresses the issue of training generalized skills, and discusses the advantages of community-based instruction, the realities of implementation with learners with severe behavior problems, offering minimally intrusive strategies for making it happen.

TITLE: Mainstreaming preschoolers: Children with health impairments

AUTHOR: Human Development Services

PUBLICATION INFORMATION: 1986

U.S. Department of Health and Human Services
Office of Human Development Services
Administration for Children, Youth and Families
Head Start Bureau
Washington, DC 20201

Written for day care, nursery school and other preschool staff, for specialists like diagnosticians and therapists, and for parents of young children with health impairments, this is a basic and useful resource. It answers questions like "what is mainstreaming" and "where to find help in your area." It provides descriptions of the various kinds of health impairments that could affect a preschooler, using specific cases, and the ways in which the impairments can interfere with the child's growth and development. It suggests the modifications that an educational program, like day care, might require, depending on the type and severity of the impairment. It offers guidelines for broad issues like enlisting parent participation or developing an IEP, and for specific activities like story reading and field trips.

The primary resources the book focuses on are the Head Start programs, but other resources outside of Head Start, including professional and parent associations and other organizations, books, films, and slide tapes, are also briefly described. The appendix lists medical tests, screening and diagnostic procedures and gives a chart of normal development from infancy to six years of age. This book is one of a series of eight books on children with handicaps; the other seven books address emotional disturbance, hearing impairment, learning disabilities, mental retardation, physical (orthopaedic) handicaps, speech and language impairments, and visual handicaps.

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TITLE: Beyond separate education: Quality education for all

AUTHOR: Lipsky, D. K., & Gartner, A. (Eds.)

PUBLICATION INFORMATION: 1989

Paul H. Brookes
P.O. Box 10624
Baltimore, MD 21285-0624

Creating exemplary programs for all students is the main impetus for this book. The editors wish to challenge the division between special and regular education, and offer suggestions for combining the dual systems. This book contains four sections: (1) the background of special education and the current situation in education, (2) a discussion of schools and classrooms with a focus on integration, (3) teacher preparation, roles of parents,, advocates, and the relationships of students in integrated settings, and (4) the future of public policy and the views of disability in current models of special education. The book would be helpful to teachers, administrators, and those who are interested in public policy in education.

The book attempts to cover many issues in mainstreaming, and does so in a coherent, theoretical manner. It is an interesting combination of strategies and policy issues, and the focus of the book is broad. Sections of the book will appeal to

people for various reasons, though the whole book might not be read in its entirety by every reader. Nevertheless, it is a compelling volume.

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TITLE: Program quality indicators (PQI): A checklist of most promising practices in educational programs for students with severe disabilities

AUTHOR: Meyer, L.

PUBLICATION INFORMATION: 1985

PQI Checklist
TASH
7010 Roosevelt Way N.E.
Seattle, WA 98115

The checklist is designed for use by school district personnel and consumer groups to evaluate and guide program development. By scoring a particular program on each item, program strength and need areas can be identified. This assessment of how well the program compares to the Program Quality Indicators in each area can then be used to plan program development goals for the immediate future, based upon both obvious discrepancies and identified program priorities.

The checklist is organized into six program components: 1) Program philosophy, 2) Program design and student opportunities for learning, 3) Systematic instruction and performance evaluation, 4) IEP development and parent participation, 5) Staff development and team collaboration, and 6) Facilities and resources.

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TITLE: Teaching autistic children: A functional curriculum approach

AUTHOR: Neel, R. S., Billingsley, F. F., McCarthy, F., Symonds, F., Lambert, C., Lewis-Smith, N., & Hanashiro, R.

PUBLICATION INFORMATION: 1983

College of Education
Project IMPACT
Experimental Education Unit WJ-10
University of Washington
Seattle, WA 98195

This volume is a curriculum package which represents a comprehensive application of principles involved in instructional planning and service delivery which is referenced to the criterion of ultimate functioning. Each of the components (assessment, decision-making, and instructional planning/implementation) was field-tested in various public school programs in the Seattle area. A particularly useful item in the manual is the home-school inventory process and form, which the

teacher and parents complete independently and then use to reach mutual agreement on IEP goals which are based upon perceived needs and strengths. The manual also includes procedures to assess the student's present level of functioning on daily routines--including adaptations needed for individual component skills--and deliver instruction in the context of actual, activity routines as they occur in current and future environments. The curriculum has been replicated in various school districts outside the state of Washington, including schools in such diverse areas as Alaska and Minnesota.

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TITLE: Severely handicapped students in regular schools: A progress report: Milwaukee public schools integration efforts

AUTHOR: Nietupski, J., Hamre-Nietupski, S., Schultz, G., & Ockwood, L.

PUBLICATION INFORMATION: 1980

Milwaukee Public Schools
Division of Exceptional Education and
Supportive Services
P.O. Drawer 10K
Milwaukee, WI 53201

This report provides a practical guide to the establishment and maintenance of integrated public schools for students with moderate/severe special learning needs. The material is based on the authors' experience with integration efforts in the Milwaukee Public Schools during 1979 and 1980. Detailed accounts of building-level strategies and results along with concept or summary papers constitute the major body of the report. The appendices provide listings of media to be used in sensitizing students in regular education classes to the needs of students with special learning needs. Perhaps, the most impressive part of this report is found in the detailed accounts of classroom teachers concerning their experiences with integration. These are (or should be) required reading for teachers in training. Other audiences would find many fresh and exciting ideas in this report as well. This report stands as yet another affirmation of the fact that students with (mild-profound) special learning needs can and do profit greatly from education in normative settings. The report also discusses the positive effects of such integration on typical students and their teachers as well.

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TITLE: The comprehensive local school: Regular education for all students with disabilities

AUTHOR: Sailor, W., Anderson, J., Doering, K. F., Filler, J., Goetz, L., & Halvorsen, A. T.

PUBLICATION INFORMATION: 1989

Paul H. Brookes
P.O. Box 10624
Baltimore, MD 21285-0624

The main premise of this book is that all children with special needs should have the option of receiving an appropriate education at their local school, which a student would attend if he or she were not labeled. The authors present a comprehensive educational service delivery model which extends the concept of the LRE to the local school. Five age groups are presented in this book for discussion of regular education placements: preschool, elementary, middle school, secondary school, and young adulthood. School administrators would be primarily interested in this book.

The authors pose the following question: "How much and under what conditions should students with disabilities be integrated in regular classes?" Today, many people believe that this question does not adequately cover the issue. Many advocates of integration would argue that all students, regardless of disability, should be educated within the regular classroom. The authors believe that the LRE is a useful concept in education. However, many other leaders in the field believe that as long as the LRE concept exists, full integration and equality for all students will not be realized.

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TITLE: Severely handicapped students: An instructional design

AUTHOR: Sailor, W., & Guess, D.

PUBLICATION INFORMATION: 1983

Houghton Mifflin Company
1 Beacon Street
Boston, MA 02108

The purpose of this book is to provide teachers, therapists, and other professionals serving severely disabled students, with an organizational framework from which to design educational programs. The authors have combined a precise, behavioral approach to instruction with curricular decision making that is based on cognitive theory as well as environmental demands.

The book is divided into 12 chapters, beginning with an overview of recent legal and legislative actions that support the right of severely disabled individuals to receive educational services in the least restrictive setting. This overview is followed by two chapters which provide a technical analysis of how motivation and stimulus control contribute to the learning process. Subsequent chapters serve to broaden the perspective by describing curriculum strategies that are consistent with preparing severely disabled students to function in integrated community environments. Individual chapters are devoted to curriculum approaches for infants and preschool children, elementary school children, and secondary-level students. A final chapter is

devoted to descriptions of support systems for adults. Throughout, the text uses illustrations and examples to convey how the approaches might be applied to students with severe multiple disabilities.

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TITLE: Health-impaired children deserve a break

AUTHOR: Shayne, M. W., Walker, D. K., Perrin, J. M., & Moynihan, L. C.

PUBLICATION INFORMATION: 1987

Principal, 66(3), 36-39.

This article makes the case for the inclusion of children with chronic medical problems in regular schools. It points out that schools will have to examine and adapt in the areas of health and supportive services; absence and attendance policy; and life planning, transition, and career preparation in order to be truly responsive to the needs of these students. The article ends with seven recommendations for action on the national and local scene which will positively influence the quality of life available to students with chronic health problems.

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TITLE: Integration of students with severe handicaps into regular schools

AUTHOR: Stainback, S., & Stainback, W.

PUBLICATION INFORMATION: 1985

The Council for Exceptional Children
1920 Association Drive
Reston VA 22091-1589

On the heels of the authors' initial call for a merger of special and regular education, comes this slim but effective book that offers an abundance of practical procedures and strategies to facilitate the total integration of students with severe disabilities into regular schools. Although written primarily for classroom teachers, both special and regular education, the book can be recommended equally highly to professors, researchers, administrators, and parents.

The book is divided into five sections. While section one gives an overview of the context of integration of students with severe disabilities, section two describes an easy-to-use checklist for assessing available opportunities and suggests ways to promote interactions. Section three addresses the education of nonhandicapped students about individual differences and section four focuses on teaching students with severe disabilities social and other skills to facilitate their integration. Section five looks at the organizational arrangements needed to prepare schools and non-school community settings for integration, and describes some successful integration programs throughout the nation.

TITLE: Educating all students in the mainstream of regular education

AUTHOR: Stainback, S., Stainback, W., & Forest, M.

PUBLICATION INFORMATION: 1989

Paul H. Brookes
P.O. Box 10624
Baltimore, MD 21285-0624

This book is an excellent compilation which addresses the merging of special and regular education, and for educating all students in the mainstream of regular education. Six major areas are outlined in the text: (1) an introduction and historical overview of education integration and a rationale for merging special and regular education; (2) three case examples of situations involving integration; (3) strategies for enhancing quality and equality in heterogeneous integrated schools; (4) educational practices for integrated classroom settings; (5) broadening integration and equality beyond schools through family participation and community participation; and (6) concerns relevant to the education of students in integrated schools and classrooms. This book would appeal to a wide range of readers including all teachers, parents, students, administrators and advocates.

The organization of this book is excellent. Throughout the text there are "points to ponder" which challenge the reader. The chapter on assessment procedures for the classroom relies heavily on quantitative approaches, and could have included qualitative strategies as well. This book is state-of-the-art in terms of integrated education.

TITLE: Support networks for inclusive schooling

AUTHOR: Stainback, W., & Stainback, S.

PUBLICATION INFORMATION: 1990

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

There has been much discussion in the field of education regarding full inclusion of students who have disabilities in the regular classroom. For those who have embraced this philosophy, this timely volume will provide assistance with the actual nuts-and-bolts of promoting friendships among all students. The book is divided into three sections: part one describes inclusive schooling and support networking; part two focuses on specific supports that can be utilized to assist students and classroom teachers; part three emphasizes how parents, administrators, and community members can work together to create supportive and caring schools.

This book will be very helpful for teachers who want to know more about the nature of providing support to students who have disabilities in their classroom, as well as they, as teachers, can acquire their own support. Parents will find this book helpful also in determining what the potential is for their child's well-being in the school setting, with the proper supports in place. The editors have done an excellent job of combining many thoughtful chapters from a variety of concerned individuals in the field of education.

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TITLE: Purposeful integration... Inherently equal

AUTHOR: Taylor, S. J., Biklen, D., Lehr, S., & Searl, S. J.

PUBLICATION INFORMATION: 1987

TAPP Project
Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, MA 02116

This is an excellent and informative guide discussing the many questions and issues related to school integration. Especially useful for parents trying to understand what integration means for their child and the many issues related to school personnel, laws, teachers that they and their child may face. The book offers guidelines in what to look for in defining a good program. Legal aspects are also presented along with a section on the least restrictive environment. This concise manual offers support and clarification to parents around many common issues related to school integration.

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TITLE: Chronically ill children in school

AUTHOR: Walker, D. K., & Jacobs, F. H.

PUBLICATION INFORMATION: 1984

Peabody Journal of Education, 61(2), 28-74

This article traces the historical and philosophical determinants of current school programming for chronically ill children. It describes the range of available educational options and placement patterns for students with chronic conditions at various grade levels. The most common problems connected with these conditions are examined; these include problems confronted by the individual student as well as those the school faces as it attempts to plan and program effectively. Recommendations are made that focus on the delivery of educational services, future policy directions, and needed research.

TITLE: Design of high school programs for severely handicapped students

AUTHOR: Wilcox, B., & Bellamy, G. T.

PUBLICATION INFORMATION: 1982

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

Wilcox and Bellamy, who have had extensive experience in developing programming for school-aged individuals and adults with severe handicaps, have combined their unique perspectives in this book which focuses on strategies for preparing high school students for the adult world. A comprehensive model of secondary services is described which is based on current principles and practices such as chronological age-appropriateness, integration, community-referenced instruction, and transitional services.

The book is divided into 13 chapters which address curriculum planning, classroom operation, instructional methodology, transitional planning, and program administration. An entire chapter is devoted to each of the following programmatic areas: vocational; leisure and recreational; and independent living. Many of the chapters contain useful examples of skill listings, evaluation checklists, IEP objectives, and schedules. Although this book is intended for teachers working with secondary-aged students, it can also serve as a valuable resource for teachers at the elementary school level. Teachers of students with severe multiple disabilities, however, may find that the book does not provide enough examples of how the information might apply to their students.

INTEGRATED EMPLOYMENT: SERVICES AND SUPPORTS

Some of the most exciting and creative progress in community integration of people with severe disabilities is now being made in efforts to place and support people in regular jobs in the community where they earn a decent wage and have opportunities to interact with nondisabled people. As is always the case in fast moving fields, the literature lags behind the exciting progress being made in this area. With this in mind the following reviews provide basic information to those who are interested in supported work.

TITLE: An instructional guide for training on a job site: A supported employment resource

AUTHOR: Barcus, M., Brooke, V., Inge, K., Moon, S., & Goodall, P.

PUBLICATION INFORMATION: 1987

Virginia Commonwealth University
Rehabilitation Research and Training Center
VCU Box 2011
Richmond, VA 23284-0001

This manual is written for vocational service providers who are directly involved with on-site job training of people with severe disabilities. The process and the corresponding forms included are based on work done in vocational services during the past nine years at Virginia Commonwealth University through Project Employability and the Rehabilitation Research and Training Center. The authors point out that there are many approaches to vocational training and that this manual is not intended to be an all inclusive source of information on job site training. Instead this is a detailed procedural guide for professionals who wish to implement one particular approach to job site training.

TITLE: Supported employment: Parental involvement

AUTHOR: Beckett, C., & Fluke, D.

PUBLICATION INFORMATION: 1988

Exceptional Parent, 18(1), 20-26.

This article is primarily directed toward parents. The authors emphasize the importance of parental involvement in supported employment issues. At the same time they recognize that in order for parents to be effective advocates for their children, they must understand the concept of supported employment. The chapter describes a training program for parents that was developed to address the parents' many questions and concerns around supported employment.

TITLE: Supported employment: A community implementation guide

AUTHOR: Bellamy, G. T., Rhodes, L. E., Mank, D. M. & Albin, J. M.

PUBLICATION INFORMATION: 1988

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book is a practical guide on how to make supported employment a reality. It gives practical advice for developing supported employment programs, including the initial planning stages, collecting information, and developing a program proposal. The authors also discuss four different approaches to consider, when establishing a supported employment program. These are: (1) individual supported jobs in community businesses, (2) enclaves, or work stations, in industry, (3) mobile work crews, and (4) other small businesses. In discussing these approaches the authors emphasize that each approach must meet the federal requirements for supported employment as well as five requirements the authors call "organizational accomplishments" which they recommend be used by supported employment organizations as a framework for planning, management and evaluation. It should be noted that some authors in the area of supported employment would argue that only individual job placements could truly meet the requirements outlined in the book. Despite this disagreement the book offers practical advice on how to develop, organize, operate, manage, and evaluate supported employment efforts and should be a practical resource for those who are involved in the planning and organizaion of supported employment programs, including parents, educators, and human service workers.

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TITLE: The Madison strategy for evaluating the vocational milieu of a worker with severe intellectual disabilities

AUTHOR: Brown, L., Solner, A. U., Schwartz, P., Courchave, B., Kampschroer, E. F., VanDeventer, P., & Jorgenson, J.

PUBLICATION INFORMATION: in press - available January 1991

TASH
7010 Roosevelt Way, N.E.
Seattle, WA 98115

This volume's primary purpose is to delineate a strategy that can be used to evaluate the vocational milieu of a worker with severe intellectual disabilities. It offers an alternative to many of the currently used vocational evaluation strategies and is based on the assumption that all people with severe disabilities can work in integrated work environments. This work has been underway since 1986, and has gone through four revisions. It was sent out for review to selected various agencies, service providers and public schools that are involved in vocational training, and was extensively revised based on their input. The latest version has been field-tested with 45 local individuals, and contains a checklist covering the evaluation areas.

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TITLE: The new Victors: A progressive policy analysis of work reform for people with very severe handicaps

AUTHOR: Ferguson, D. L. & Ferguson, P. M.

PUBLICATION INFORMATION: 1986

Mental Retardation, 24(6), 331-338.

The authors begin this article by reviewing the history of reform in human services and special education. They then use the experience of earlier reform movements as a guide for examining current efforts to expand the vocational opportunities available to individuals with severe disabilities. In this light, they discuss the meaning of work and the current state of the labor force. Their historical perspective leads them to caution against a new form of unintended exclusion of people with severe disabilities from community participation which can result from over reliance on economic utility at the price of social integration. In conclusion they make five specific suggestions for future research, policy, and practice to act as a guide for avoiding the mistakes of past reform movements.

TITLE: Toward supported employment: A process guide for planned change

AUTHOR: Gardner, J. F., Chapman, M. S., Donaldson, G., & Jacobson, S. G.

PUBLICATION INFORMATION: 1988

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

Conversion from sheltered to integrated employment is a major change for an organization. This valuable book's premise is that such change can be managed successfully. The book begins by concisely summarizing existing theory and knowledge about change, including methods for introducing change, design of strategic and long range action plans, and coping with internal and external resistance to change. It emphasizes involvement of all affected parties in the change process, including board members, staff at all levels, people with disabilities, parents, and community organizations. The book goes on to apply the conceptual material to conversion more specifically to supported employment, discussing such areas as leadership, organization readiness, market analysis, assessing staff needs, skills, and capabilities, organizational structure needed to maintain supported employment, and coordination with other human service providers and private sector organizations. The authors insist that the values and norms of the organization are critical to the change process, and properly emphasize the need to clarify and communicate these throughout the process.

It is up to the reader, however, to define the values used to drive the change process, as the authors only suggest some general values. This may but does not need to present problems for readers who prefer the individualized placement approach.

TITLE: Vocational education for persons with handicaps

AUTHOR: Gaylord-Ross, R. (Ed.)

PUBLICATION INFORMATION: 1988

Mayfield Publishing Company
1240 Villa Street
Mountain View, CA 94041

This comprehensive textbook describes the multifaceted process of career preparation for students with disabilities. It is divided into four major sections having to do with vocational special education. The first part, dealing with policies and professional roles, contains chapters on legislation and policy, career education, professional roles and practices, and community living. The second section, on vocational assessment and preparation, looks at assessment, programming, and secondary vocational training. The third section describes and explores economic issues, the business perspective, the ecology of the workplace, and adult employment programs. The last section contains four chapters that look at vocational education for persons with different levels or types of disabilities--mild disabilities, severe disabilities, physical disabilities, and sensory disabilities. While the authors of these chapters include well-known writers in every aspect of the field, readers may have difficulty with their complexity. Several chapters are excellent, however.

Ian Pumpian, Elizabeth West, and Holly Shepard, for example, contributed a chapter entitled "Vocational Education of Persons with Severe Handicaps." This chapter starts by raising some fundamental value questions that provide the basis for developing and evaluating services for people with severe disabilities. The authors argue that consistent answers to such questions are essential to understanding the current direction and debate concerning training and employment. The authors also criticize some of the current supported employment practices, for example, for either excluding people with the most severe disabilities or selecting pseudointegration models, as has been the case with some enclave and work crew programs. The chapter reviews some of the school trends and initiatives that have contributed to the evolution of supported work and discuss current trends and initiatives in adult services.

TITLE: Vocational education for students with handicaps

AUTHOR: Gaylord-Ross, R.

PUBLICATION INFORMATION: 1989

In D. Biklen, D. L. Ferguson, & A. Ford (Eds.), Schooling and disability: Eighty-eighth yearbook of the National Society for the Study of Education, Part II (pp. 203-231). Chicago: University of Chicago Press.

In this article, the author describes a qualitative study of vocational integration of people with developmental disabilities in five European countries: Denmark, Great Britain, Italy, Switzerland, and West Germany. Based on five months of travel through these countries, where the author conducted numerous site visits; completed over 250 interviews; and reviewed 500 documents, the author describes patterns of vocational integration in these five countries, as compared to efforts underway in the United States. The author concludes by identifying and discussing five important variables which can facilitate social change toward integrated work: (1) "political will", (2) the presence of a "charismatic leader(s)", (3) the presence of "model demonstration programs", (4) the level of "instructional technology" among staff, and (5) the "economic state" of a particular country.

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TITLE: Supported employment: Federal policies and state activities related to integrated work opportunities for persons with developmental disabilities

AUTHOR: Gettings, R. M., & Katz, R. E.

PUBLICATION INFORMATION: 1987

National Association of State Mental
Retardation Program Directors
113 Oronoco Street
Alexandria, VA 22314

The aim of this report is twofold. First, it explores how federal and state policies influence the participation of people with severe disabilities in the general work force. Second, it explores the current activities of state MR/DD (Mental Retardation/Developmental Disability) agencies in the area of supported employment programs. Part one summarizes recent federal legislation and demonstrates the various, often interrelated ways, in which federal policies can influence (either positively or negatively) the establishment of supported employment programs across the nation. Part two describes how many states are actively converting day activity programs into supported employment. Part two is based on a state-by-state survey conducted by the National Association of State Mental retardation Program Directors.

The purpose of the report is to offer a descriptive analysis of current events. Therefore, it does not draw conclusions or contain recommendations. However, because it discusses many crucial issues it contributes to a greater awareness of the role of state agencies in helping workers with severe disabilities to find and retain jobs in the community. The report also demonstrates how various federal policies influence the availability and accessibility of employment opportunities for individuals with severe disabilities.

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TITLE: The social integration of supported employees: A qualitative study

AUTHOR: Hagner, D.

PUBLICATION INFORMATION: 1989

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $5.35 plus 10% shipping and handling

This study examines the social interactions that occured within supported employment settings in Syracuse, NY, between workers with disabilities and their co-workers without disabilities. It also examined the job supports at these work settings, to understand the relationship between formal support services and natural job supports.

This study should affect the supported employment field profoundly. Its major finding was that even though employees were physically integrated on their jobs, they were often socially isolated, not because of their disabilities but because of how their jobs were set up. That is, their jobs tended to be structured in ways that inhibited natural social interaction, and their job coaches did not teach (and often discouraged) participation in social customs. The author, who spent hundreds of hours observing co-worker interactions on jobs, found that workers talk, joke, and give assistance to each other on a regular basis, and that there is often an informal mentoring system by which new workers are socialized into jobs. He concluded that job coaches sometimes bring a human service perspective and a narrow job task focus to a work setting, being unaware of or ignoring the wider "culture" of a workplace. Many supported employment services will recognize themselves in his descriptions of practices that tended to exclude supported employees from participating in the workplace culture, which could have been a powerful source of natural support.

TITLE: Payment mechanisms for community employment: Realities and recommendations

AUTHOR: Hagner, D., Nisbet, J., Callahan, M., & Moseley, C.

PUBLICATION INFORMATION: 1987

Journal of The Association for Persons with Severe Handicaps, 12(1), 45-52.

The article describes the payment mechanisms that are available to reimburse workers with severe disabilities for performed work. The authors demonstrate that even if the current regulations do provide mechanisms whereby workers with severe disabilities can both work in fully integrated settings and receive pay, the options available for these workers have serious limitations. Current regulations allow for a few different types of employment by workers with severe disabilities and the authors discuss the advantages and disadvantages of each of those: (1) competitive employment at, above, or below minimum wage, (2) contracted employment through a rehabilitation agency, and (3) self-employment. The discussion includes suggestions for utilization of different available payment options. The article concludes with recommendations for changes both on the level of service provision and public policy.

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TITLE: Facilitating natural supports in the workplace: Strategies for support consultants

AUTHOR: Hagner, D. C., Rogan, P., & Murphy, S. T.

PUBLICATION INFORMATION: in press

Journal of Rehabilitation

This article discusses strategies for facilitating natural supports in the workplace, including strategies used by typical workers, ways of byilding interactions and supports into job designx, utilizing typical business procedures for job training, using the routines found in the workplace culture, and identifying commonalities between co-workers with and without disabilities. It recommends adoption of a consultant rather than a coaching role by those employed to give support to the worker with the disability, thereby maximizing the natural support potential of a workplace. While the authors emphasize the tentative nature of their recommendations, they outline a large number of practical strategies that deserve strong consideration by supported employment agencies.

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TITLE: Employment outcomes for people with moderate and severe disabilities: An eight-year longitudinal analysis of supported competitive employment

AUTHOR: Hill, M. L., Wehman, P. H., Kregel, J., Banks, P. D., & Metzler, H. M. D.

PUBLICATION INFORMATION: 1987

Journal of The Association for Persons with Severe Handicaps, 12(3), 182-189.

(The following article is one in a series of three articles that all focus on the benefits and costs of supported employment. All three articles were published in the same issue of JASH. The other two articles (by Noble & Conley and by Rhodes, Ramsing & Hill) are not included in this listing but are worth reading.)

This article presents information on the benefits and costs associated with supported competitive employment and is based on an eight-year analysis. This is one of the few benefit-cost analyses that has focused on people with mental retardation who have received supported competitive employment services over an extended period of time. The authors' analysis showed a substantial savings to society by utilizing the model of supported competitive employment. Their results also showed a significant financial benefit to workers with moderate and severe disabilities. The authors conclude that hopefully this information will provide encouragement to those who make fiscal decisions related to supported competitive employment.

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TITLE: Supported employment: What about those in Medicaid funded day treatment and day activity centers?

AUTHOR: Laski, F., & Shoultz, B.

PUBLICATION INFORMATION: 1987

Word From Washington, May 1987, 12-14.

In this article the authors remind us that supported employment is designed for individuals with severe disabilities who have traditionally been served in day activity programs. At the same time some of the supported employment programs have been used to serve people with mild disabilities who have had, or should have had, other vocational services to achieve and maintain competitive employment. The authors analyze how the federal funding and administration of the Medicaid Program have affected vocational services for people with severe disabilities and argue that these funding mechanisms make it a virtual certainty that states utilizing Title XIX funds for day programs will continue to exclude adults with severe handicaps from vocational services, including supported employment.

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TITLE: Getting employed, staying employed: Job development and training for persons with severe handicaps

AUTHOR: McLoughlin, C. S., Garner, J. B., & Callahan, M. (Eds.)

PUBLICATION INFORMATION: 1987

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This excellent and practical book investigates the processes involved in developing jobs in integrated settings, and methods for facilitating employment opportunities for people with severe disabilities. The first part deals with the problems of sheltered work. Based on an analysis of cost effectiveness and programmatic ideologies, the first chapter demonstrates how these workshops are inherently inadequate. The authors suggest that sheltered work environments should be systematically phased out in favor of employment in integrated settings. The rest of the book serves as a practical manual for job development, placement and training for people with severe disabilities. This book provides unusually valuable guidelines for people who are interested in developing integrated individualized jobs for people with severe disabilities.

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TITLE: Helping persons with severe mental retardation get and keep employment: Supported employment issues and strategies

AUTHOR: Moon, S. W., Inge, K. J., Wehman, P., Brooke, V., & Barcus, M. J.

PUBLICATION INFORMATION: 1990

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book was written to address the exclusion of persons with severe and multiple disabilities from supported employment training and placement programs--an exclusion that is well documented at this point in time, despite the fact that this is the group for whom supported employment was intended. This book provides information specifically related to helping people with the most severe disabilities get and keep real jobs in regular work places.

The first half of the book examines a variety of issues, including strategies for assessment, present performance outcomes for people with severe mental retardation, and job placement for students in transition to adulthood, and should challenge the reader to recognize what remains to be done in implementing supported employment. The last five chapters are more technical in nature, and can serve as a day-to-day guide for persons directly involved in programs. These chapters describe methods that have worked and that can be replicated. This is an excellent resource for program administrators and staff as well as parents and people in state decision-making positions.

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TITLE: Achieving success in integrated workplaces: Critical elements in assisting persons with severe disabilities

AUTHOR: Nisbet, J., & Callahan, M.

PUBLICATION INFORMATION: 1987

In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities (pp. 184-201). New York: Teachers College Press, 1234 Amsterdam Avenue, New York, NY 10027.

This chapter provides an overview of the elements of successful job placements for people with severe disabilities. Specifically the authors outline the rationale for a fully individualized approach to job placement, including methods for coordinating services across the various agencies which are usually involved in the life of a person with a severe disability. The authors also address key issues related to supports and skill development with special emphasis given to natural supports and the development of on-the-job relationships.

TITLE: Real jobs

AUTHOR: People First of Ontario

PUBLICATION INFORMATION: 1988

Entourage, 3(1), 41 & 49.

This short article describes the third annual meeting of People First of Ontario, held on October 30, 1987. The meeting was titled: "Real Jobs in the Community" and focused on the difference between segregated (workshop) jobs and integrated (real) jobs. In the form of two resolutions, People First of Ontario pledged to act on their own behalf and agreed to make "Real Jobs" a major project in the coming year by approaching the local associations for community living and going to the provincial government to urge that real jobs be found for people labelled mentally retarded.

TITLE: New roles for parents

AUTHOR: Pressman, H.

PUBLICATION INFORMATION: 1987

The Exceptional Parent, 17(1), 36-40.

This article describes how parents of young people with special needs are making an impact on the employment opportunities of these young people. The author gives many examples from across the country about the important role parents can play in influencing vocational opportunities ranging from applying for state grants, to establishing vocational training programs in schools, to training other parents to be advocates for their children, to establishing corporations to provide jobs.

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TITLE: Vocational evaluation in supported employment

AUTHOR: Rogan, P., & Hagner, D.

PUBLICATION INFORMATION: 1990, January/February/March

Journal of Rehabilitation

There are problems with the traditional approaches to vocational evaluation for people with severe disabilities. This article discusses ways in which supported employment has been adopted within traditional vocational evaluation practices, and provide arguments supporting the need for reexamination and revamping of traditional ideologies and practices. Finally, the authors offer a model of vocational evaluation that is compatible with the principles of supported employment.

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TITLE: Competitive employment: Issues and strategies

AUTHOR: Rusch, F. R. (Ed.)

PUBLICATION INFORMATION: 1986

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book is a significant contribution to the literature on community employment of people with disabilities. Section one consists of six chapters. Chapter one describes obstacles to competitive employment and program options to overcome them. Chapters two through six describe and discuss five programs which use different approaches to achieve competitive employment. Section two consists of eleven chapters and focuses on competitive employment methods. The chapters address a number of specific techniques and strategies in relation to competitive employment programs, from initial assessment to long term follow-up. Section two also has two chapters on developing training sites and community jobs. Both contain useful suggestions and information. Section three explores competitive employment

issues in seven chapters. Most of these chapters present contemporary service delivery issues in vocational programming. The book concludes with an epilogue on integrated work in the form of an interview with Dr. Lou Brown.

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TITLE: Supported employment: Models, methods, and issues

AUTHOR: Rusch, F. R. (Ed.)

PUBLICATION INFORMATION: 1990

Sycamore Publishing Company
P.O. Box 133
Sycamore, IL 60178

This is a comprehensive book (25 chapters) covering many aspects of supported employment, with an emphasis on support as the hallmark of the approach and integration as its most defining contribution. The first 14 chapters, which deal with historical developments, experiences in several states, characteristics of programs, and methods, include some good discussions of worker-directed placement and promoting natural support and social acceptance. The chapter on worker-directed placement, for example, emphasizes the importance of organizing services so that workers with severe disabilities are assisted to achieve employment and other life goals that are personally defined, rather than controlled or established by the service provider. In this discussion, the worker provides the guidance and the professional the technology the worker uses to realize his or her choices. The difficult process of transformation of traditional supported employment services to a program that understands and supports consumer choices is explained and a model for doing so is proposed.

The next 7 chapters focus on issues in supported employment, including incentives and disincentives, cost-benefit analysis, conversion from adult day care, current national issues, and future opportunities, questions, and concerns. A final section focuses on the transition from school to work, looking at secondary vocational training, community planning, personnel preparation, and state planning.

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TITLE: The impact of integrated employment on leisure lifestyles

AUTHOR: Sandys, J., & Leaker, D.

PUBLICATION INFORMATION: 1988

Entourage, 3(1), 17-23.

This article focuses on the way in which integrated work can influence the use of leisure time of workers with disabilities. The authors argue that after-hour socializing with fellow workers is in the majority of cases greater in community jobs than in sheltered workshop jobs. While most supported employment programs do not

focus specifically on the issue of relationship building the authors argue that integrated work has, at least for some workers with disabilities, resulted in opportunities to interact and develop relationships with non-disabled people.

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TITLE: Establishing effective community-based training stations

AUTHOR: Stainback, W., Stainback, S., Nietupski, J., & Hamre-Nietupski, S.

PUBLICATION INFORMATION: 1986

In F. Rusch (Ed.), Competitive employment: Issues and strategies.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This chapter describes a rationale for the use of community-based training sites uring the school years and suggests guidelines for developing and maintaining these sites. The chapter is aimed primarily at school personnel who are unfamiliar with the use of community-based training sites.

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TITLE: From school to work: A vocational transition model for handicapped students

AUTHOR: Wehman, P., Kregel, J., & Barcus, J. M.

PUBLICATION INFORMATION: 1985

Exceptional Children, 52(1), 25-37.

In this article, the authors describe a three-stage vocational transition model for young people with disabilities as they move into adulthood. A major part of the article is directed toward emphasizing the necessity for functional curriculum in integrated educational settings with community based training opportunities. In addition the authors recommend the use of a written individualized transition plan and emphasize the importance of parental input. The authors conclude by recommending that all school systems provide regular follow-up of special education graduates on a minimum of every two to three years in order to determine the effectiveness of transition plans in reducing the extraordinarily high unemployment rate of people with disabilities.

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TITLE: A report on competitive employment histories of persons labeled severely mentally retarded

AUTHOR: Wehman, P., Hill, J. W., Wood, W., & Parent, W.

PUBLICATION INFORMATION: 1987

Journal of The Association for Persons with Severe Handicaps, 12(1), 11-17.

This article is based on the authors' in-depth study of 21 individuals with severe mental retardation working in integrated competitive supported employment settings. The purpose was to describe the employment experiences of these 21 individuals over an eight-year period from 1978-1986. The data described in the article presents both positive and negative commentary on competitive employment prospects for people with severe mental retardation and concludes by making suggestions for improving the quality of vocational interventions, including more creative and comprehensive job development and more powerful and systematic intervention techniques.

TITLE: Vocational rehabilitation and supported employment

AUTHOR: Wehman, P., & Moon, S.

PUBLICATION INFORMATION: 1988

Paul H. Brookes Publishing Co.
P.O. Box 10724
Baltimore, MD 21285-0624

This book provides an extensive and at times inspirational overview of the supported employment field. It discusses philosophies, ideas, and models of supported employment as well as practical issues such as interagency perspectives, funding, management of rehabilitation agencies engaged in conversion to supported employment, inservice training for supported employment personnel, marketing strategies and other implementation issues. The last section of the book discusses supported employment applications with different groups of people, specifically people with autism, traumatic brain injury, severe and persistent mental illness, physical disabilities, and severe and profound mental retardation. An early chapter, by M. Sherril Moon and Susan L. Griffin, discusses the advantages and disadvantages of individualized placement, enclaves, mobile work crews, and small business options in a balanced way that demonstrates the clear advantages of individualized placement for the worker and the agency.

TITLE: Transition from school to work: New challenges for youth with severe disabilities

AUTHOR: Wehman, P., Moon, S. M., Everson, J. M., Wood, W., & Barcus, J. M.

PUBLICATION INFORMATION: 1988

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book is a practical guide to planning and implementing successful transition programs for adolescents with severe disabilities. The book focuses on sustained employment as the primary goal of transition. The authors argue that they do not intend to minimize the importance of community living competence, but rather to emphasize the influence that employment can have on all dimensions of an individual's life. Throughout the book the authors provide a variety of sample forms, charts, tables, and lists for individual transition plans, program evaluation and interagency cooperation. Appendices include guidelines for parent involvement in vocational training and a selected annotated bibliography on supported employment and transition. This book should be useful for practitioners, parents, researchers, students and advocates.

TITLE: Implementing a community-based vocational training model: A process for systems change

AUTHOR: Wershing, A., Gaylord-Ross, C., & Gaylord-Ross, R.

PUBLICATION INFORMATION: 1986

Education and Training of the Mentally Retarded, 21(2), 130-137.

This article describes procedures necessary to implement a community-based instructional model for vocational training. Issues involved in facilitating systems change are addressed. Strategies for use in gaining administrative support, in programming, community site selection and development, parent involvement, and employer participation are provided. The benefits of community-based vocational training for students with disabilities, in preparation for transition to employment opportunities, are illustrated through presentation of a case study.

TITLE: Expanding employment opportunities and options through major barrier removal

AUTHOR: Whitehead, C. W.

PUBLICATION INFORMATION: 1986

Employment-Related Services
901 Sixth Street, SW #609A
Washington, DC 20024

This article describes the major changes in legislation created by the 99th Congress, which impact favorably upon employment opportunities for people with developmental disabilities. Specifically outlined are changes in: (1) the Rehabilitation Act of 1973; (2) the Education for all Handicapped Children Act; (3) the Fair Labor Standards Act; (4) the Work Incentive Provisions of the Social Security Act; (5) the Tax Revisions of 1986; and (7) the Consolidated Omnibus Budget Reconciliation Act (COBRA).

The author also addresses related actions taken by the Social Security Administration in an effort to reduce barriers to employment and concludes by discussing seven issues that remain as barriers to employment.

The following two journals have each devoted a whole issue to transition from school to work and vocational issues.

Exceptional Children. April 1985, 53(6).

Special Issue: The Transition from School to Adult Life

This issue of Exceptional Children is devoted to the transition from school to adult life. Most of the eleven articles are more of an overview than a detailed description of programming and how to go about doing things.

Exceptional Parent, January/February 1988, 18(1).

Special Issue: Educational Planning

This issue of Exceptional Parent is devoted to educational planning, transition from school to work and vocational issues. All the articles and information in the issue are primarily directed toward parents who have daughters or sons with disabilities.

RECREATION AND LEISURE OPPORTUNITIES

This section highlights some excellent materials on supporting children and adults in integrated community recreational, leisure, and cultural activities. These materials emphasize the importance of such activities and decry the lack of attention by the field people's needs to enjoy ordinary community leisure settings and events.

TITLE: Strategies for developing individualized recreational/leisure programs for severely handicapped students

AUTHOR: Ford, A., Brown, L., Pumpian, I., Baumgart, D., Nisbet, J., Schroeder, J., & Loomis, R.

PUBLICATION INFORMATION: 1984

In N. Certo, N. Haring, and R. York (Eds.), Public school integration of the severely handicapped: Rational issues and progressive alternatives.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

The authors suggest that recreational and leisure needs, crucial areas in the lives of people with severe disabilities, are often ignored in educational programming. The net result of this failure of the educational system is that the adult with severe disabilities is left with a very limited repertoire of leisure skills and is often dependent on a limited number of organized, segregated, "special" leisure-time activity programs.

In outlining the strategies to be used to formulate an individualized recreation/leisure component for the school curriculum, the authors provide a very practical sketch of the ecological approach to community-based programming which should be suitable in the full range of settings providing services to people with severe handicaps. There are seven stages to the process: (1) conducting ecological inventories; (2) summarizing inventory information; (3) establishing priorities--with a discussion of 19 dimensions to be considered in establishing individual program priorities; (4) conducting a discrepancy analysis; (5) using partial participation and proposing individualized adaptations; (6) determining individualized objectives; and (7) designing the specifics of the individual's program.

TITLE: The pursuit of leisure: Enriching lives with people who have a disability

AUTHOR: The G. Allan Roeher Institute (complied by D. Gold & J. McGill)

PUBLICATION INFORMATION: 1988

The G. Allan Roeher Institute
4700 Keele Street, Kinsmen Building
York University
Downsview, ON M3J 1P3
CANADA

This book is a collection of short chapters on integrated recreation and leisure for people with disabilities. It includes articles which provide strategies for service providers to promote integrated recreation opportunities, and articles about recreation and leisure by both persons labeled as disabled and their parents. The chapters explore a range of issues, including: the development of "leisure identities" (reprint of an article by Judith McGill: integration through community associations and organizations; "regenerating community" (reprint of a paper by John McKnight); promoting cooperative versus competitive play; and leisure and friendships.

TITLE: Leisure connections: Enabling people with a disability to lead richer lives in the community

AUTHOR: The G. Allan Roeher Institute (compiled by D. Gold & C. Crawford)

PUBLICATION INFORMATION: 1988

The G. Allan Roeher Institute
York University, Kinsmen Building
4700 Keele Street
Downsview, ON M3J 1P3
CANADA

This manual provides many useful ideas and strategies for promoting integrated leisure and friendship opportunities for people with disabilities. Emphasis is placed on the importance of leisure in people's lives, based on a broad definition of leisure as including activities with others or alone, and activities that are more formal and organized as well as those that are informal and/or spontaneous. The authors also focus on the importance of friendships in people's lives, and the idea that it is people's relationships with others that give the most meaning to their leisure experiences.

The manual is designed for use by support groups or circles convened to assist a person with disabilities develop and/or increase his or her leisure opportunities and connections. It outlines a 10-step process, which can be used to assist either children

or adults. The recommended role of friends and other supports is one of a "facilitator" of increased connections and activities.

The 10 steps include thought-provoking questions and exercises to help guide group strategizing and planning. They focus on issues such as: thinking about the nature of leisure and the role it plays in everyone's lives; assisting the person to express wishes or dreams; developing a collective vision with the person; brainstorming about leisure options for the person, beyond just "programs" or classes; preparing for challenges that may be encountered; and on-going support and planning to increase and maintain leisure connections. The appendices contain additional information and ideas about the nature of friendship, as well as a sample listing of the many possible types of leisure opportunities can be found in a single community.

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TITLE: Integrating children and youth with disabilities into community recreation agencies: One agency's experience and recommendations

AUTHOR: Heyne, L. A., Amado, R. S., & Denelle, D.

PUBLICATION INFORMATION: 1987

The Jewish Community Center of the
Greater St. Paul Area
1375 St. Paul Avenue
St. Paul, MN 55116

Since 1984, the Jewish Community Center of the Greater St. Paul area has conducted a model demonstration project to integrate children and youth with disabilities into the Center's regular programs and classes. The goals of the integration efforts have been three-fold: (a) to develop socialization and friendships between youngsters with and without disabilities; (b) to teach new recreation and leisure skills; and (c) to provide opportunities for children and youth with disabilities to participate in normalized, everyday community activities.

This monograph contains information about integration at the Center in the following areas: rationale for integration; background to the project; funding; practical, step-by-step description of the integration process; networking with other community organizations; suggestions for managing challenging behaviors; Board of Directors and lay committee input and involvement; problems encountered and solutions generated; project outcomes; and forms for intake and evaluation. In conclusion, the authors emphasize the benefits of integration for all children, not only those with disabilities.

There is a wealth of information presented here about strategies for providing supports to children and youth with disabilities in a way that facilitates and enhances integration. It should be very useful for other agencies or individuals who are interested in promoting integration in recreation and leisure activities.

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TITLE: Journal of Leisurability

PUBLICATION INFORMATION:

Leisurability Publications, Inc.
36 Bessemer Court, Unit 3
Concord, ON L4K 3C9
CANADA

The Journal of Leisurability is a quarterly journal which publishes articles, with a strong Canadian focus, concerned with leisure, disability, community, advocacy, and integration. The journal regularly centers its content around a theme, with feature and support articles related to the theme. Each issue includes a section called "Current Research," reserved for research related to leisure and people with disabilities. In addition, the journal invites brief articles for a "Sharing Program Ideas" section, to allow people involved in programming, advocacy, and social action activities to share interesting or innovative approaches they are using or developing.

TITLE: Participation: Expanding community and leisure experiences for people with severe handicaps

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1981

The G. Allan Roeher Institute
Kinsmen Building, York University
4700 Keele Street
Downsview, ON M3J 1P3
CANADA

This book grew out of a collective effort of a group of people in Canada known as the Recreation Council of the National Institute on Mental Retardation. The book is designed to assist communities in the initiation, planning, and implementation of a process for expanding community and leisure experiences to include people with severe handicaps. The authors sees community integration as a process, and each chapter in the book represents one step in this process. STEP ONE: Generating interest in the participation of individuals with severe handicaps; STEP TWO: Identifying and developing community support; STEP THREE: Implementing plans; STEP FOUR: Preparing support staff; and STEP FIVE: Expanding community and leisure experiences.

Good and practical guidelines are provided through each of the five steps. The process described will be useful for those who want to assist people with severe disabilities to participate in a wide range of community and leisure experiences. The author also gives advice on how to overcome barriers to integration.

TITLE: Our leisure identity

AUTHOR: McGill, J.

PUBLICATION INFORMATION: 1987

Entourage, 2(3), 23-25.

The article begins with the assertion that it is our leisure experiences that give richness to our lives. Friendships are often built or strengthened through leisure involvements. Yet, people with disabilities are often not assisted to develop their leisure identities. Leisure activities for people with disabilities are often highly supervised, structured, and segregated. The author argues that "spontaneity and choice, two essential ingredients of leisure, are seen as not being practical or even possible." Within the article, an example is provided of a man who was assisted and supported to develop his leisure interests. This led to membership in two local clubs, a provincial club, and the formation of some friendships. In conclusion, the author emphasizes the need for concerned parents, advocates, and human service providers to provide adequate supports to assist people with disabilities to develop strong leisure identities, become members of local community clubs and organizations, and build and maintain friendships with others.

TITLE: Review of task analytic leisure skill training efforts: Practitioner implications and future research needs

AUTHOR: Nietupski, J., Hamre-Nietupski, S., & Ayres, B.

PUBLICATION INFORMATION: 1984

Journal of The Association for Persons with Severe Handicaps, 9(2), 88-97.

The authors review recreation/leisure training programs that have been conducted with students having moderate and severe disabilities. Emphasis is placed on those which involve data based task analytic, instructional efforts as well as recent curriculum volumes or position papers. Implications for practitioners are provided, as well as future research needs in the recreation/leisure skill domain. Some of the points made include: leisure skills should be selected on the basis of those activities performed by nondisabled students in a wide variety of integrated settings; instruction must extend beyond the classroom into integrated home and community settings; instructors should conduct social validation of skills to be taught, obtaining information from students without disabilities as to what skills are important; more effort needs to be placed on assisting students with severe disabilities and physical limitations to take part in integrated leisure activities.

TITLE: Community recreation and persons with disabilities

AUTHOR: Schleien, S. J., & Ray, M. T.

PUBLICATION INFORMATION: 1988

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book begins with an overview of the historical background and philosophical basis of integrated recreation. The authors provide detailed information on ways to facilitate participation in community recreation activities/settings. Their ecological approach involves, in part, an in-depth Environmental Analysis Inventory, which includes information on: (1) the appropriateness of the recreation activity/setting; (2) general program and participant information; (3) an activity/discrepancy analysis; and (4) further activity considerations. The book also includes information on other issues such as: partial participation, adaptations, cooperative grouping arrangements, and overcoming obstacles to community recreation integration. It concludes with a section describing several positive integrated recreation efforts, and an extensive appendix section with copies of building survey forms, environmental analysis inventory forms, a leisure interest survey, an annotated bibliography, and other information.

Overall, Schleien and Ray provide a wealth of detailed information about how to create increased opportunities for integrated recreation. The authors firmly believe that most of the "barriers" to integrated recreation can be overcome through use of the right strategies. This book would be a particularly useful resource for people who are involved in developing integrated recreation options for people with disabilities.

TITLE: Leisure and recreation: Preparation for independence, integration, and self-fulfillment

AUTHORS: Voeltz, L. M., Wuerch, B. B., & Wilcox, B.

PUBLICATION INFORMATION: 1982

In B. Wilcox & T. Bellamy (Eds.), Design of high school programs for severely handicapped students.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

The authors begin with the recognition that leisure skills have not typically been considered an essential part of special education programs. The chapter first

presents a definition of the "leisure domain," describing the characteristics of leisure environments and activities and identifying particular issues of concern for leisure educators of secondary students with severe disabilities. A second section outlines the benefits of leisure preparation in school programs. And, a third section of the chapter offers some strategies for leisure training, and suggested directions for future work in the design of programs and development of materials.

Emphasis is placed on the importance of choice and personal preferences in leisure activities. Therefore, according to the authors, "a major objective of leisure education should be to provide the individual with options, both by making activities available and by ensuring that the individual has the necessary skills to exercise meaningful choices and enjoy the activities he or she selects." They also emphasize the importance of involving a student's family in decisions about priority areas for leisure education.

In their conclusion, the authors argue that special programs and facilities should be phased out, and instead adaptations should be made to make regular settings accessible. Segregated environments should not be maintained for those who lack the "prerequisites" to function in integrated environments. Instead, effort needs to be placed on assisting and supporting all students, including those with severe disabilities, to participate in integrated recreation and leisure activities and settings.

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TITLE: The kid from Cabin 17

AUTHOR: Walker, P., & Edinger, B.

PUBLICATION INFORMATION: 1988, May

Camping Magazine, 18-21.

This article focuses on the integration of Chauncey, a child with severe and multiple disabilities, into a regular camp. It describes strategies used to assist him to participate in camp activities, and encourage interaction with other campers and camp staff. It concludes with some lessons learned about integration based on this experience: (1) it is important to help foster a sense of belonging or membership in group activities; (2) it is important for regular staff and nondisabled children to be able to see ways in which someone with severe disabilities can participate in a wide range of activities; (3) it is important to recognize the ways that regular staff (rather than specially trained "disability" workers) can support children with disabilities; (4) it is important that integration occur on a small-scale basis; and (5) it is important that the scheduling of time for children with disabilities, as for other children, not be too rigidly structured; that they have time just to "hang out." The article illustrates ways in which Chauncey came to be a valued member of camp; how other children's acceptance of and friendship with him came from spending time with him and getting to know him. As a result, they began to focus on his similarities, personal qualities, and abilities, rather than on differences, stereotypes, and disabilities.

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TITLE: Beyond the classroom: Involving students with disabilities in extracurricular activities at Levy Middle School

AUTHOR: Walker, P., Edinger, B., Willis, C., & Kenney, M. E.

PUBLICATION INFORMATION: 1988

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $3.30 plus 10% postage and handling

This report describes efforts to involve students with severe disabilities from one classroom in extracurricular activities within their middle school. Students participated in activities such as intramural basketball, girls' volleyball team, track, the Spanish Club, the Computer Club, and the Ski Club. The paper provides detailed description of all aspects of the project, including: how it was conceptualized and structured; the role of the classroom teacher; the role of the support staff; and the perspectives of activity leaders (i.e., coaches, club advisors, etc.), parents, and other students on inclusion of students with disabilities in these extracurricular activities. This project provides a nice illustration of the cooperative effort between a human service agency and a public school in use of respite funds to provide supports for student participation in after-school activities. Examples are given which illustrate ways in which the students with disabilities experienced sense of school membership and school spirit that went far beyond the walls of the special education classroom.

SUPPORTING PEOPLE WITH CHALLENGING BEHAVIORS

From the massive literature on this topic we have selected a very small number of resources. Our criterion for selection was adherence to the guidelines of the Association for Persons with Severe Handicaps on intrusive interventions, which read as follows:

> *Whereas, in order to realize the goals and objectives of The Association for Persons with Severe Handicaps, including the right of each severely handicapped person to grow, develop, and enjoy life in integrated and normalized community environments, the following resolution is adopted:*

Whereas, educational and other habilitative services must employ instructional and management strategies which are consistent with the right of each individual with severe handicaps to an effective treatment which does not compromise the equal important right to freedom from harm. This requires educational and habilitative procedures free from indiscriminate use of drugs, aversive stimuli, environmental deprivation, or exclusion from services; and

Whereas, TASH supports a cessation of the use of any treatment option which exhibits some or all of the following characteristics: 1) obvious signs of physical pain experienced by the individual; 2) potential or actual physical side effects, including tissue damage, physical illness, severe stress, and/or death, that would properly require the involvement of medical personnel; 3) dehuman-ization of persons with severe handicaps because the procedures are normally unacceptable for nonhandicapped persons in community environments; 4) extreme ambivalence and discomfort by family, staff, and/or caregivers regarding the necessity of such extreme strategies or their own involvement in such interventions; and 5) obvious repulsion and/or stress felt by nonhandicapped peers and community members who cannot reconcile extreme procedures with acceptable standard practice;

Resolved, that The Association for Persons with Severe Handicaps' resources and expertise be dedicated to the development, implementation, evaluation, dissemination, and advocacy of educational and management practices which are appropriate for use in integrated environments and which are consistent with the commitment to a high quality of life for individuals with severe handicaps.

(Adopted October, 1981)

These guidelines mean that most of the standard materials on behavioral interventions were excluded from consideration. We feel that aversive and highly restrictive interventions are inappropriate for anyone, and especially for people who are highly vulnerable because of their disabilities.

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TITLE: A time-limited intensive intervention program model to support community placement for persons with severe behavior problems

AUTHOR: Donnellan, A. M., LaVigna, G. W., Zambito, J., & Thvedt, J.

PUBLICATION INFORMATION: 1985

Journal of The Association for Persons with Severe Handicaps, 10, 123-131.

This article describes a program model for meeting the needs of a widely diverse range of people using nonaversive strategies to deal with their severe behavior problems in community environments. Follow-up data is presented which supports the effectiveness of the model. In addition, data from parents and an independent review committee provides support for the social validity of the programs goals and methods.

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TITLE: Analyzing the communicative functions of aberrant behavior

AUTHOR: Donnellan, A. M., Mirenda, P. L., Mesaros, R. A., & Fassbender, L. L.

PUBLICATION INFORMATION: 1984

Journal of The Association for Persons with Severe Handicaps, 9(3), 201-212.

The authors suggest that when individuals lack conventional modalities of communication they are likely to attempt to communicate using means which a service provider may perceive as problem behavior. Three types of interventions are offered to provide severely handicapped persons with an alternative to this socially unacceptable type of communication. A strategy and an instrument for analyzing the communicative function of behavior (i.e., understanding the message the severely handicapped person is sending) is also provided. The perspective advocated in this article is significant because it reminds us that the person we are trying to change has an individual point of view and may well be sending a message which is not being properly received.

TITLE: An educative approach to behavior problems: A practical decision model for interventions with severely handicapped learners

AUTHOR: Evans, I. M., & Meyer, L. H.

PUBLICATION INFORMATION: 1985

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book presents a decision model, accompanied by detailed procedures for implementation, for dealing with the excess or problem behavior of persons with severe disabilities in a functional and adaptive way. Practitioners are provided with a practical, step-by-step model for planning interventions with people with severe problem behaviors in the context of habilitative, community-based programs across the school years and beyond. Separate chapters describe current "most promising practices" in educational curricula for learners with severe handicaps into which this approach should be integrated; the empirical research base on causes of and interventions with people with severe behavior problems; a field-tested decision model to select priority intervention goals within the context of the IEP; strategies to intervene with excess behavior in normalized, community environments; and evaluation principles and procedures to judge the significance of interventions. Each of the

procedures and strategies described in the book have been demonstrated to be effective in integrated, community settings, and all are consistent with the TASH resolution on intrusive interventions.

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TITLE: Use of aversive procedures with persons who are disabled: An historical review and critical analysis

AUTHOR: Guess, D., Helmstetter, E., Turnbull, H. R., & Knowlton, S. (Ed. by P. Campbell, with Epilogue by F. Laski)

PUBLICATION INFORMATION: 1987

The Association for Persons with Severe Handicaps (TASH)
7010 Roosevelt Way, N.E.
Seattle, WA 98115

This monograph presents a thorough and scholarly critique of the use of aversive procedures such as punishment, negative reinforcement, and overcorrection with people with disabilities and especially severe handicaps. The manual includes an evaluation of the effectiveness of aversive procedures, an analysis of aversive procedures as described in published studies, a comparison of procedures used with people with disabilities with those used on other populations, a discussion of public and professional silence on aversives in the area of disabilities, a description of depersonalization, and a summary and recommendations. The manual contains an exhaustive list of references and a series of excellent tables summarizing the research literature on aversive procedures.

This monograph will be most useful to policymakers, researchers, and others who are involved in the controversy surrounding the use of aversive procedures with people with disabilities. Those who oppose aversives generally will find support for their position, although the authors concentrate on analyzing aversive interventions rather than demonstrating the feasibility of alternatives. A strength of this manual from one perspective is a weakness from another. The authors attempt to provide an objective and balanced analysis of the issues relating to the use of aversives. If anything, they understate the case against aversive procedures. While this approach may be effective in reaching people undecided in the controversy, the manual lacks a sense of moral outrage at the punishment and pain too often inflicted upon people with disabilities.

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TITLE: A problem solving approach to challenging behaviors: Strategies for parents and educators of people with developmental disabilities and challenging behaviors

AUTHORS: Janney, R., Black, J., & Ferlo, M.

PUBLICATION INFORMATION: 1989, August

Jim Black, SETRC
Syracuse City School District
501 Park Street
Syracuse, NY 13203

Why do some children with developmental disabilities behave in ways that are difficult to handle? Are some behavior problems so serious that they legitimate aversive treatment, pain infliction or the causing of emotional distress? If one chooses not to punish, how does one respond to behaviors that are disturbing and dangerous? These are questions that are constantly raised by both parents and educators of children who are developmentally delayed. There are number of ethical questions and issues of humane treatment that are also closely associated with the above mentioned queries. This manual therefore offers various non-aversive alternatives to address challenging behaviors at home, at school and in the community.

The repertoire of problem solving strategies that are offered in this book can be characterized as gentle, preventative, normal, educational, individualized and ongoing. It involves effective planning through a team approach that avoids placing blame and emphasizes honesty and accountability. The authors offer valuable suggestions on how to define the particular behavior problem, ways of prioritizing aspects of the behavior that need to be changed, methods of gathering information, developing a sound theory and acting on it in non-aversive and humane ways. The manual offers blank problem solving forms that can be used for any behavior intervention.

This manual is a very useful resource for professionals and parents. Written in a simple style and explained thoroughly with adequate examples, it is easy to comprehend.

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TITLE: Community supports for people labelled by both the mental retardation and mental health systems

AUTHORS: Knoll, J., & Racino, J. A.

PUBLICATION INFORMATION: 1988

Center on Human Policy
200 Huntington Hall
Syracuse University
Syracuse, NY 13244-2340

COST: $2.30 plus 10% postage and handling

This monograph discusses the implications that come with being "dually" diagnosed. i.e., persons who are labelled as having both mental illness and mental retardation. Persons with dual diagnoses generally fall into three groups: those who have had a history in the criminal justice system, those who receive services from psychiatric professionals and those whose challenging behaviors could be classified as "symptomatic of an underlying disturbance." As the authors point out, the problem

lies more in the heart of two very divergent theoretical points of view--the holistic and the behavioristic. After a brief discussion of these theories, the authors speak in favor of services that emphasize commitment, individuality, flexibility, supports and human relationships.

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TITLE: Alternatives to punishment: Non-aversive strategies for solving behavior problems

AUTHOR: LaVigna, G. W., & Donnellan, A. M.

PUBLICATION INFORMATION: 1986

Irvington Press
740 Broadway
New York, NY 10003

This book provides a comprehensive overview of how to implement a positive approach to behavioral programming in the community. It reviews the standard behavioral practices and delineates how they can be implemented with in this positive framework. This book will be particularly valuable to behavioral psychologists working with community programs.

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TITLE: Cognitive counseling and persons with special needs: Adaptive approaches to the social context

AUTHOR: Lovett, H.

PUBLICATION INFORMATION: 1985

Praeger Publishers
One Madison Avenue
New York, NY 10175

This book is about seeing the unique value of every individual regardless of the labels society has pasted on them. Indeed, Lovett does write about the counseling--the true professional--relationship in the fullest sense: helping the individual have the greatest possible range of choices in his or her life. The forum for this discussion is provided as Lovett highlights the ways in which behaviorism, a powerful tool for aiding personal growth, has been transformed into a methodology for control. In particular, he shows how an emphasis on clinical research has led to the misuses of many interventions in the lives of people with severe disabilities. His central point is that by attempting to directly translate procedures used in highly controlled institutional settings into the real lives of people, service providers and their behavioral consultants have frequently lost sight of the individual they claim they are helping. Lovett sees the basic principle of behaviorism as remaining valuable, but

points out how implementation is radically transformed when the social context of an intervention is taken into consideration.

Except for the title, this book is written in a clear, understandable style. Anyone with a minimal understanding of behaviorism should be able to learn from it. However, you will be disappointed if you pick this volume up looking for a how-to-do-it-manual of behavioral strategies. One of its central lessons is that all such "resources" will be most valuable when they find their way to the circular file.

Teachers, residential providers, and consultants will find Lovett rewarding reading. In addition this book may be particularly valuable as a tool for educating local "generic" mental health providers and beginning psychologists about people with severe and profound mental retardation. One of the most telling sections contains the author's reflections on the inadequacy of his own professional preparation for working for people with severe disabilities.

And finally, make no mistake about it, as Lovett speaks about the right to live in the community, freedom of choice, respect, and dignity he clearly means everyone. His numerous examples from his own experience make it clear that this man places no arbitrary limits on who is a member of the human community. His books should lead all of us who work for people with severe disabilities to seriously examine the attitudes we bring to our work.

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TITLE: Gentle teaching: A non-aversive approach to helping persons with mental retardation

AUTHOR: McGee, J. J., Menolascino, F. J., Hobbs, D. C., & Menousek, P. E.

PUBLICATION INFORMATION: 1987

Human Sciences Press, Inc.
Fifth Floor, 233 Spring Street
New York, NY 10013

This book presents "gentle teaching" as a positive and humanizing approach to dealing with people who have challenging behaviors. As described by the authors, gentle teaching rejects punishment and aversive behavioral interventions and stresses the importance of integrating behaviorism with humanism. The book provides a philosophical rationale for gentle teaching, a description of techniques, examples of gentle teaching, and a response to common questions about gentle teaching ("What you can try if...?"). Throughout the book, the authors present concrete suggestions. The book is directed toward caregivers and others who are directly involved in providing services to people who have challenging behavior.

This book will be most useful to people who are committed to nonaversive interventions and do not need to be convinced that aversive procedures are ineffective and dehumanizing. The authors do not attempt to present the research evidence on the effectiveness of either aversive interventions and punishment, on the one hand, or gentle teaching, on the other. The strengths of this book are that it presents a humanizing posture toward people who have often been abused and dehumanized and that it offers some practical ideas.

TITLE: Modification of excess behavior: An adaptive and functional approach for educational and community contexts

AUTHOR: Meyer, L. H., & Evans, I. M.

PUBLICATION INFORMATION: 1986

In R. H. Horner, L. H. Meyer, & H. D. Fredericks (Eds.), Education of learners with severe handicaps: Exemplary service strategies (pp. 315-350). Baltimore: Paul H. Brookes.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

The authors of this chapter give service providers an overview of the adaptive and functional approaches which are available for addressing challenging behaviors in people with severe disabilities. They provide a summary review of the empirical evidence which supports the effectiveness of these approaches. This review demonstrates that the technological knowledge is adequate for supporting people with challenging behaviors within the context of integrated community environments. What is demonstrated in this chapter is the ability to place this highly developed technology within a framework which sees it as a tool for improving the lives of individuals and not as an end in itself.

TITLE: Non-aversive intervention for behavior problems: A manual for home and community

AUTHOR: Meyer, L. M., & Evans, I. M.

PUBLICATION INFORMATION: 1989

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

The manner in which a caregiver thinks about behavior determines the manner in which s/he will interact with a person with a disability. This manual is created on this basic assumption. Thus in offering examples of non-aversive interventions for behavior problems it emphasizes more neutral terms such as "excess behavior" in place of "behavior problems," acknowledging also that every behavior has communicative intent. Certain excess behaviors that persons with disabilities exhibit reflect the person's needs to acquire more appropriate social skills and the desire to have access to new activities. Meyer and Evans describe as a guiding philosophy that as one attempts to teach new behavioral skills, it is also necessary that those involved take

particular care not to compromise the individual's life style and dignity. This can only be achieved if learning can be considered a reciprocal encounter.

Created as a training manual for professionals and paraprofessionals, the authors describe a wide variety of issues. Insisting that there can be an educative approach to behavior problems, the manual goes on to describe excess behaviors and offers strategies for teaching adaptive alternatives for home and communities as well as to support behavior change. The entire intervention is deeply embedded in a perspective which addresses the extent to which a person's daily lifestyle reflects a quality-of-life that would be considered personally meaningful and socially valued.

Replete with carefully construed examples and detailed descriptions and explanations, this manual is a very useful resource for all professionals who are looking at more humane ways of intervention for challenging behaviors.

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TITLE: Individualizing justice for offenders with developmental disabilities: A descriptive account of Nebraska's IJP model

AUTHOR: Morton, J., Hughes, D., & Evans, E.

PUBLICATION INFORMATION: 1986, Spring-Summer

Prison Journal, LXVI, 52-66.

Following the trend of the individualized education plan, (IEP), Crime and Community Inc., Nebraska, has developed an Individualized Judicial Plan (IJP). The IJP model emphasizes the use of the least restrictive community alternative to incarceration as early as possible in the criminal justice process while still holding the individual accountable for his/her behavior.

Persons with mental retardation do not commit many violent crimes. The IJP is designed so that nonviolent offenders do not spend time in a prison where due to their disability, recidivism is more likely to occur. The plan works on an the basis of a multi-disciplinary, multi-agency model, where there is increased networking and coordination of the human services, the criminal system, advocacy and voluntary systems. It explores very innovative means of ensuring that the person is accountable for his/her actions; at the same time, the agencies involved make commitments for which they are accountable. The IJP describes these commitments and expectations in concrete terms.

This article offers new insights into the process of providing adequate support to the individual with mental retardation who is an offender.

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TITLE: The language of pain: Perspectives on behaviour management

AUTHOR: Rioux, M. H., & Yarmol-Franko, K. (Eds.)

PUBLICATION INFORMATION: 1988

The G. Allan Roeher Institute
4700 Keele Street, Kinsmen Building
York University
Downsview, ON M3J 1P3
(416) 661-9611

The language of pain is a collection of essays by professionals, family members and self-advocates who believe it is wrong and ineffective to use painful "therapies" in managing behavior. Especially powerful is the description by a woman of her sister's experiences in traditional behavior management programs. As her sister's behavior became more injurious, more painful techniques were used on her, while the family stood by helplessly, unable to bring her home and unable to stomach the assaults on her dignity and person. Each writer makes a strong plea for a more humane approach to altering or dealing with abusive behavior.

The book argues for understanding, human bonding, and interaction as the basis for attempts to change behavior. It points out that methods that have nothing to do with the infliction of pain can be used with success by professionals and families. The book presents a good and impassioned plea for change but is not a "how-to" manual. Instead, it is valuable because it emphasizes the beliefs and postures that must underlie any attempt to interact with another human being.

TITLE: Autism and life in the community: Successful interventions for behavioral challenges

AUTHOR: Smith, M. D.

PUBLICATION INFORMATION: 1990

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

One area that is often neglected by policy makers, researchers and professionals is the area of adult issues in autism. This book seeks to fill this gap. It provides practical guidelines that meet the "training and management needs" of persons with autism, that can be used in the context of community integrated school and residential settings. The book thus effectively answers questions on the service systems that are provided, behavioral assessment, intervention and modifications that can be implemented and vocational skills that can be taught. An interesting section of the book deals with self management and interpersonal skills which prove to be particularly useful to the adult, especially in the context of community living. A number of examples have been used to effectively illustrate the techniques that have been described.

Though the strategies that have been offered are useful in analyzing and problem-solving of behavioral challenges, this book falls short on one score. By describing a highly structured and manipulable environment and with the increased utilization of "technical" terms to describe and explain behavior, there is a certain

human element that is missing in the book. Behavioral challenges also arise through an inability to create and sustain meaningful relationships with others. And this is one aspect that the book does not even touch upon.

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The following articles describe particular non-intrusive interventions which have been effectively used in community settings.

Barton, L. E., & Barton, C. L. (1985). An effective and benign treatment of rumination. Journal of the Association for Persons with Severe Handicaps, 10, 168-171.

Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. Journal of Applied Behavior Analysis, 18, 111-126.

Donnellan, A. M. (1984). The criterion of the least dangerous assumption. Behavioral Disorders, 9, 141-150.

Evans, I. M., & Voeltz, L. M. (1982). The selection of intervention priorities in educational programming of severely handicapped preschool children with multiple behavior problems (ERIC Report #ED 240 765). Honolulu: University of Hawaii Departments of Psychology and Special Education.

Favell, J. E. (1973). Reduction of stereotypes by reinforcement of toy play. Mental Retardation, 11, 21-23.

Favell, J. E., McGimsey, J. F., & Schell, R. M. (1982). Treatment of self-injury by providing alternate sensory activities. Analysis and Intervention in Developmental Disabilities, 2, 83-104.

Gaylord-Ross, R. (1980). A decision model for the treatment of aberrant behavior in applied settings. In W. Sailor, B. Wilcox, & L. Brown (Eds.), Methods of instruction for severely handicapped students (pp. 135-158). Baltimore: Paul H. Brookes.

Konczak, L. J., & Johnson, C. N. (1983). Reducing inappropriate verbalization in a sheltered workshop through differential reinforcement of other behavior. Education and Training of the Mentally Retarded, 18, 120-124.

O'Neil, P. M., White, J. L., King, C., & Carek, D. (1979). Controlling childhood rumination through differential reinforcement of other behavior. Behavior Modification, 3, 355-372.

Peterson, R., & Peterson, L. (1968). The use of positive reinforcement in the control of self-destructive behavior in a retarded boy. Journal of Experimental Child Psychology, 6, 351-360.

Rose, T. L. (1979). Reducing self-injurious behavior by differentially reinforcing other behavior. AAESPH Review, 4, 179-186.

Smith, M. D. (1985a). Managing the aggressive and self-injurious behavior of adults disabled by autism. Journal of the Association for Persons with Severe Handicaps, 10, 228-232.

Smith, M. D. (1985b). Working with autism: Social skills training in the workplace. Maryland Psychologist, March.

Smith, M. D., & Belcher, R. (1985). Teaching life skills to adults disabled by autism. Journal of Autism and Developmental Disorders, 15(2), 163-175.

Smith, M. D., & Coleman, D. (1986). Managing the behavior of adults with autism in the job setting. Journal of Autism and Developmental Disorders, 16(2), 145-154.

Smith, M. D., & Levy, E. (1986). The use of self-control with an adolescent disabled by autism in the transition from school to work. Available through Community Services for Autistic Adults and Children (CSAAC), 751 Twinbrook Parkway, Rockville, MD.

Woods, T. (1982). Reducing severe aggressive and self-injurious behavior: A nonintrusive, home-based approach. Behavioral Disorders, 7(3), 180-188.

SUPPORTING PEOPLE WITH COMPLEX PHYSICAL AND/OR HEALTH NEEDS

This section contains a variety of resources including materials on supporting people with chronic medical needs and/or who have been labelled as "technology assisted" and materials on supporting people with extensive physical needs and/or multiple disabilities. In our review of the literature, we found that materials developed for one group (e.g., chronically ill children) were not always easily available or seen as applicable to other groups (e.g., children labelled medically fragile and developmentally disabled). In order to increase exchange across these fields, we have combined annotations of materials related to many of these areas. We also strongly recommend the sections addressing issues relevant to people with complex physical and/or health needs (e.g., "Community Living for Children," "Families," "Community Living for Adults," "Integrated Employment," etc.).

TITLE: Home care for children: An annotated bibliography

AUTHOR: ACCH (Association for the Care of Children's Health)

PUBLICATION INFORMATION: 1984

ACCH
3615 Wisconsin Avenue, N.W.
Washington, DC 20016

This excellent resource contains brief reviews of 110 books and journal articles on home care of children with serious medical or handicapping conditions. They were selected to provide a theoretical and practical groundwork for home care development, evaluation and research. A number of citations on home care of adults are included since there is more extensive literature in this area and many of the practical issues are the same. The citations are organized into the following topic areas: general models of home care; specific illnesses or conditions; preparing, educating, and training the care team and the family for home care; terminal care; educating the child; respite care; and funding. People interested in the topic of home care are strongly urged to obtain a copy.

TITLE: The child and health care: A bibliography

AUTHOR: ACCH (Association for the Care of Children's Health)

PUBLICATION INFORMATION: 1983

ACCH
3615 Wisconsin Avenue, N.W.
Washington, DC 20016

This booklet presents a listing of what the reviewers consider to be the best available materials dealing with issues surrounding the involvement of families and children with the health care system. The approximately 1200 resources listed here are divided into the following areas: developmental information and resource work; children and hospitalization; parents and families in health care settings, play and the sick child: preparation for medical events; children with specific illness; dealing with chronic illness; dealing with death; ambulatory pediatrics; selected children's books; and selected films for children, families, and professionals. As with other ACCH materials, this is an excellent and comprehensive resource.

TITLE: Home care manual series

AUTHOR: American Family Health Institute

PUBLICATION INFORMATION: 1986

Springhouse Corporation
111 Bethlehem Pike
Springhouse, PA 19477

This organization has produced a series of 32 page booklets which outline in clear jargon-free text and illustrations basic procedures in health care. The titles in the series include: Bedsores, Care basics, Cast care, Colostomy care, Comfort measures, Crutches and canes, Danger signs, Dressings and bandages, Exercises, Feeding tubes and pumps, Help for the care giver, Hospital beds, Hygiene, Incontinence care, Injections, Medications, Oxygen therapy, Parenteral nutrition, Self-help aids, Suctioning, Tips for feeding the sick, Tracheostomy care, Urinary catheter care, and Walkers and wheelchairs. These are useful resources for non-medical personnel, family members, and people with special needs themselves.

TITLE: Approximating the norm through environmental and child-centered prosthetics and adaptive equipment

AUTHOR: Campbell, P. H., Green, K. M., & Carlson, L. M.

PUBLICATION INFORMATION: 1977

In E. Sontag, J. Smith, & N. Certo (Eds.), Educational programming for the severely and profoundly handicapped. Reston, VA: Council for Exceptional Children

This article, which is technical but clearly written, provides practical information on selecting equipment, designing prosthetics, and developing programs for people with severe physical and orthopedic impairments. The article contains numerous illustrations and case examples. The conclusion lists sources of additional information. The article is written for people involved directly in services for people with severe disabilities.

TITLE: Annotated bibliography: Families of children with technology support

and

A literature review of topics concerning children who are technology-supported and their families

AUTHOR: Condry, S.

PUBLICATION INFORMATION: 1989

Beach Center on Families and Disability
Bureau of Child Research
4138 Haworth Hall
Lawrence, KS 66045

This literature review and bibliography (separate documents) provide an in-depth look at the literature on families of children with technology support. Some of the references and annotations are on materials annotated by the Center on Human Policy (in this bibliography), but also include materials not annotated here. These two pieces are good resources for anyone interested in children who are supported by medical technology.

TITLE: Low cost approaches to technology and disability

AUTHOR: Dixon, G. L., & Enders, A.

PUBLICATION INFORMATION: 1984

National Rehabilitation Information Center (NARIC)
8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319

Disguised as an annotated bibliography, this report is a gold mine for disabled persons, their families, and many direct service providers. It makes accessible for the first time, in one place, the disparate and often hidden literature on low cost technical aids for disabled persons.

This is not another book recounting the wonders of the latest high-tech innovations. Rather, this resource provides ready access to the many simple devices and adaptations which meet the needs of so many disabled persons. In the past the unavailability of a central source for this information has meant that people who see these relatively simple needs have had to constantly reinvent the wheel. This resource fills that void. The book also includes 37 pages of annotated resources.

NARIC is a good source for other materials on disability, technology, and rehabilitation.

TITLE: Financing options for home care for children with chronic illness and severe disability: A technical assistance manual

AUTHOR: Ellison, M., Bradley, V., Knoll, J. & Moore, K.

PUBLICATION INFORMATION: 1989

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This excellent resource explains and details a variety of public and private options for financing home care, including medical care, income support, social services, educational services, transportation, and housing. It also provides discussion of state programs for health insurance. These, which vary from state to state, include "high risk" insurance pools, subsidies for private health insurance, state financed or state mandated catastrophic health insurance, and mandated coverage. The book includes references and appendices with legislative acts and authorization for programs.

TITLE: Managing physical handicaps: A practical guide for parents, care providers, and educators

AUTHOR: Fraser, B. A., & Hensinger, R. N.

PUBLICATION INFORMATION: 1983

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book is intended to serve two purposes: a) to introduce physical therapists to the problems of individuals with severe handicaps, and b) to familiarize others with the fields of physical therapy and orthopedics. It is based on the experience of providing services to students with severe handicaps in the Wayne County (Michigan) public schools. Although it is written from the perspective of in-school services, this book is a valuable resource for any setting where people with severe physical handicaps are participating.

The presentation falls into three major sections: The first emphasizes the need to look beyond the disability and see the person. It also describes the nature of various handicapping conditions and offers one model for the delivery of physical therapy/orthopedic services. The second section describes and explains a wide range of physical handicaps. The final section discusses techniques for communication with, handling, and transporting people with severe impairments.

TITLE: A preliminary analysis of options to improve health insurance coverage for chronically ill and disabled children

AUTHOR: Fox, H. B.

PUBLICATION INFORMATION: 1984

Available from Author
1620 Eye Street, N.W.
Suite 300
Washington, DC 20006
(202) 429-0160

This technical report was prepared to assist the Division of Maternal and Child Health in its examination of alternative mechanisms for financing the cost of the care of children with chronic illnesses or other disabling conditions. It reviews the five basic models that exist to improve health insurance coverage for uninsured and underinsured populations. It further provides a preliminary assessment of these options in terms of their potential political viability as well as their potential benefits to families with children with disabilities. In conclusion, recommendations are offered regarding the optimal features of a new private health insurance program to meet these children's special health care financing and delivery needs.

TITLE: Children on medication

Volume I: Hyperactivity, learning disabilities, and mental retardation;
Volume II: Epilepsy, emotional disturbance, and adolescent disorders

AUTHOR: Gadow, K. D.

PUBLICATION INFORMATION: 1986

College Hill Press
4284 41st Street
San Diego, CA 92105

These books are written to provide parents, educators, and nonmedical service providers with enough information to ask informed questions and make more knowledgeable observations of the individual receiving drug therapy. Each volume includes similar introductory material on the fundamental concepts of pharmacotherapy and carries the same appendices and glossary. When available, prevalence figures are reported for each disorder and for the use of drug therapy in the general school age population and in special education programs. Both therapeutic and side effects of the drugs employed are described, along with pattern of treatment.

Volume I focuses primarily on psychotropic drug use for hyperactivity and aggressiveness. Separate chapters deal with the use of drugs with children labeled learning disabled and with children labeled mentally retarded.

Volume II describes the use of drug therapy in a variety of disorders such as epilepsy, autism, schizophrenia, and depression.

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TITLE: Functional life planning for persons with complex needs

AUTHOR: Green-McGowan, K.

PUBLICATION INFORMATION: 1987

KMG Seminars
P.O. Box 2534
Peachtree City, GA 30269

This manual covers a variety of areas: human anatomy and movement, functional assessment, principles of 24 hour planning, adaptive equipment, environmental modifications, establishing goals and objectives, principles of team planning. and individual services planning, among others. An extremely valuable resource for planning supports for people with complex medical needs.

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TITLE: Assessment and planning for health professionals

AUTHOR: Green-McGowan, K., & Barks, L. S.

PUBLICATION INFORMATION: 1985

KMG Corporation
P.O. Box 2534
Peachtree City, GA 30269

The manual is an excellent resource covering such issues as the causes of health risk for people labelled as "medically fragile," methods of collecting information including interviewing techniques and observation of the person, an evaluation schema for the neurological, musculoskeletal, respiratory, gastrointestinal/urinary, endocrine, behavioral and nutrition/eating systems, and information on the development of health improvement goals.

The assessment methodology was developed by KMG Corporation specifically for use with people labelled as "medically fragile" in order to identify and categorize their genuine level of health risk and to focus on the management methodology of improving those risks. The manual is written specifically for health professionals and has limited applicability for non-health professionals.

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TITLE: Chronically ill children in America

AUTHOR: Hobbs, N., Perrin, J., Ireys, H., Moynihan, L., & Shayne, M.

PUBLICATION INFORMATION: 1984

Rehabilitation Literature, 45(7-8), 206-213.

This article discusses the commonalities among severe chronic illnesses of childhood, reviews the definition of chronicity and severity, describes the current organization of care, costs of care and financing of care, identifies basic principles that should underlie public policy formation, and delineates the issues involved in systems change. A good resource for professionals, policy analysts, planners, and others involved in long-term policy formation.

TITLE: Come together: The experience of families with severe disabilities or chronic illness

AUTHOR: Knoll, J.

PUBLICATION INFORMATION: 1989

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This report, prepared under a contract with SKIP of New York, is the story of 48 families in New York, widely diverse in terms of cultural, ethnic, religious, and economic backgrounds but having in common their children with severe disabilities or chronic illnesses. The report is based on a study conducted for two reasons: to understand the families' experience and to communicate that experience to policy makers and service providers, and to evaluate a case management and advocacy service provided to the families by Sick Kids (need) Involved People (SKIP) of New York, Inc. This resource is one of the few that report families' experience in such rich detail, and is a "must read" for people interested in services for these families.

TITLE: Health care issues for children with special health needs and disabilities

AUTHOR: Lehr, S., & Taylor, S. J.

PUBLICATION INFORMATION: 1987

Technical Assistance for Parent Programs (TAPP)
Federation for Children with Special Needs
Suite 104, 95 Berkeley Street
Boston, MA 02116

This manual was developed as a resource for parents of children with special health needs or disabilities. The manual is designed to encourage parents to be the managers of their child's care and treatment, and to work collaboratively with health care practitioners for the benefit of the child. Section I outlines some of the key issues relating to the provision of health care and treatment for children with chronic illness and disabilities. Section II is a series of handouts that could be given to parents. Section III includes an overview of the Collaboration between Parents and Health Professionals (CAPP) Project and a reprint of the issue from Coalition Quarterly on health care issues. The last section refers the reader to additional resources.

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TITLE: The cost of providing medical care and related services to children with complex health care needs

AUTHOR: McGauley, W. P.

PUBLICATION INFORMATION: 1989

Organization Development Services, Inc.
30 Tremont Street
P.O. Box 2802
Duxbury, MA 02331
(617) 934-0161

This report, prepared under contract to SKIP of New York, Inc., is a cost comparison study. Costs were compared in three settings where children with complex health care needs receive medical care and related services. These were 1) the home (average annual cost $66.555), 2) a long-term care facility (average annual cost $169.255), and 3) acute care hospitals (average annual cost $236,250). A total of 201 children were included in the study. This study is valuable, not only for the finding that home care at $66,555 annually is much less expensive than other options, but also because it explores the issues and complexities related to costs for these children.

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TITLE: Medical care of the deinstitutionalized mentally retarded

AUTHOR: Merker, E. L., & Wernsing, D. H.

PUBLICATION INFORMATION: 1984

American Family Physician, 29(2), 228-233.

It is sometimes asserted that community doctors are not familiar with some of the concerns surrounding the medical care of people who have a history of life in an institution where they may have been exposed to Hepatitis B or been administered massive doses of unneeded drugs. Merker and Wernsing provide an overview of the role of the community physician and special concerns as they relate to patients with developmental disabilities. They highlight the significant contribution a community physician can make in meeting the needs of these people. They outline the major "specialized" medical issues which may arise. They indicate that the family practice they are associated with has been able to meet these needs including management and reduction or elimination of psychotropic medications.

TITLE: Handbook for parents

AUTHOR: Mikol, M., Shannon, K., & Schuberth, K.

PUBLICATION INFORMATION: 1984

SKIP (SICK KIDS Need INVOLVED PEOPLE), Inc.
216 Newport Drive
Severna Park, MD 21146

This handbook was prepared as a resource to families who choose to care for their "technology dependent" children at home. The handbook includes a plethora of practical information such as emergency and back up checklists, equipment worksheets, selected references, information on home care, documentation hints and information on SKIP. It is clearly written and would probably be a useful resource to service providers as well as to families. The revised version, Families to Families: The Home Care Experience, will be available at a cost of $7.50 postpaid.

TITLE: Mealtimes for severely and profoundly handicapped persons: New concepts and attitudes

AUTHOR: Perske, R., Clifton, A., McLean, B. M., & Stein J. I.

PUBLICATION INFORMATION: 1986

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

The term Mealtimes is an apt title for this marvelously written and useful book. This book does not simply describe proper "feeding" techniques for people with severe and multiple disabilities. It shows how mealtimes can be designed to be pleasant and enjoyable experiences.

Sensitively written and superbly edited, this book is a collection of articles by professionals, parents, people with disabilities, administrators, and others. The book starts out with an introduction written by Robert Perske entitled, "A Gentle Call to Revolution." Perske sets the tone for the book in this introductory chapter by stressing the need for "dignity, kindness, cooperation, and skill." The remainder of the book is divided into four sections: Value of Mealtimes, Creative Interactions, Creative Uses of People, and Helpful Settings.

This is not intended to be a how-to-do-it handbook. Instead, the purpose is "to allow a wide range of people to speak plainly about the fresh attitudes they have developed about mealtimes and the innovative things they are trying to do."

Anyone who works with people with severe and multiple disabilities should read this book. Parents, caregivers, and agency administrators will find it especially useful.

TITLE: Resources on supporting people with extensive health needs in the community

AUTHOR: Research and Training Center on Community Integration

PUBLICATION INFORMATION: 1988

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340
(315) 443-3851

COST: $4.15 plus 10% postage and handling

This information package includes an overview article on supporting people with medical and physical needs in the community and articles on family supports for children with severe disabilities and chronic illnesses in Maryland and on supporting adults with severe disabilities in the community. It also includes an annotated listing of information resources and listings of associations and agencies dealing with services to people with extensive health needs. The stance of this package is that people with extensive health needs and severe physical disabilities are and should be supported to live, work, learn, and have leisure experiences in ordinary community environments.

TITLE: Families to families: An introduction to the home care experience

AUTHORS: SKIP of Maryland, Inc., & SKIP National

PUBLICATION INFORMATION: 1988

SKIP National
500 East 83rd Street, Suite # 1B
New York, NY 10028
(212) 734-0728

Sick Kids (need) Involved People (SKIP), a national organization of parents and professionals involved in home care for children with complex medical needs (often including dependence on medical equipment like ventilators or apnea monitors), has produced this manual for parents. There are chapters on thoughts and feelings, dealing with the hospital, discharge planning, common problems, community integration, and references to resources. This is an excellent resource for families and caring staff persons.

TITLE: Surgeon General's Report: Children with special health care needs

AUTHOR: Surgeon General of the United States

PUBLICATION INFORMATION: 1987

Washington, DC: Department of Health and Human Services, Public Health Service (GPO #184-020/65654).

This report is the result of the work of an on-going task force established in 1982. It recommends a national agenda to insure a commitment to family centered care for children with special health care needs. This agenda is promoted by these 7 action steps which make up the section headings of the report: 1) Pledge a national commitment to all children with special health needs and their families, 2) encourage building community-based service systems, 3) assist in ensuring adequate preparation

for providers of care, 4) develop coalitions to improve the delivery of services, 5) establish guidelines to control costs of services, 6) encourage and support the development of adequate health care financing, and 7) continue to conduct research and disseminate information. Each section contains descriptions of 3 or 4 programs or services from around the country which offer examples of how that particular action step can be promoted.

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TITLE: Technology and children with disabilities: A guide for family members

AUTHOR: Turnbull, H. R., III

PUBLICATION INFORMATION: 1989

Beach Center on Families and Disability
Bureau of Child Research
4138 Haworth Hall
Lawrence, KS 66045

This booklet describes two federal laws in lay terms: P.L. 100-407, the Technology-Related Assistance for Individuals with Disabilities Act of 1988, and P.L. 100-360, the Medicare Catastrophic Coverage Act of 1988 (repealed late in 1989).

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TITLE: Technology-dependent children: Hospital vs. home care--A technical memorandum

AUTHOR: U.S. Congress, Office of Technology Assessment

PUBLICATION INFORMATION: 1987

U.S. Government Printing Office
Washington, DC 20402-9325
(GPO #052-003-01065-8)

This report is an effort to provide Congress with the data necessary to examine issues surrounding care for the increasing number of children who are in need of on-going nursing care or medical technology in order to survive. It begins by looking at various definitions of this population and discussing how the definition affects any efforts to project long-term need for services. It offers a definition and then makes projections based on that definition. The next section examines the comparative effectiveness and cost of hospital versus home-based care. The general conclusion here is that home care can be as effective in the medical-technical realm as hospital care of most conditions and it tends to be more cost effective. However a number of potential problems inherent in "pushing" home care (e.g., placing unrealistic demands

on families who are not up to them) are highlighted. The final section discusses sources of financing for home based care. There are major discussions of private insurance and a great deal of information on the range of medicaid waiver programs (at the time data was collected in mid-1986). There are also sections dealing with other programs which pay for home care. This report is essential reading for anyone who wishes to be informed on this issue.

TITLE: Home care for children with chronic illnesses and severe disabilities: A bibliography and resource guide

AUTHOR: Wells, A., Cox, H., Berliner, S., Bradley, V., Agosta, J., Nurczynski, P., & Bedford, S.

PUBLICATION INFORMATION: November, 1987

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

Intended to assist parents and professionals understand current issues and trends in home care for children with serious medical problems, this invaluable bibliography and resource guide summarizes relevant research and information on 1) the values involved in making home care available, 2) the needs of children and their families, 3) and financing issues related to home care.

Summaries at the front of the guide review the trends in research in the three topic areas and short annotations are provided for each bibliographic citation. It also includes appendices which contain the names and addresses of organizations with a wide range of children's health and disability issues, other published bibliographies that relate to children with special health needs, directories of services nationwide, and journals and newsletters concerned with the care of children with chronic illness. This bibliography is highly recommended as an excellent information resource.

BEYOND PAID SERVICES AND SUPPORTS

The resources in this division deal with a variety of issues that all of us, whether or not we have disabilities, see as basic needs in our lives. They are divided into the following sections:

1. Self-Determination
2. Advocacy
3. Families
4. Acceptance, Relationships and Community
5. Women and Community Care

Self-determination by people with disabilities and advocacy on their behalf are areas which people involved with people with disabilities must become familiar. Additionally, there is much discussion today about informal support (i.e., support that is given based on arguments or relationships that don't involve pay or a formal contract). The materials in the "Families," "Acceptance, Relationships and Community," and "Women and Community Care" sections approach informal support from many perspectives.

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SELF-DETERMINATION

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The fundamental right of speaking for oneself has long been denied to people with disabilities, who have usually had decisions made for them about every detail of their lives. They were, in other words, taught dependence. In the past twenty years, however, people with disabilities have organized movements (e.g., the self-advocacy movement, the independent living movement, the "psychiatric survivors" movement) that prove that that people upon whom dependence was imposed can and must speak for themselves and determine their own futures. An exciting recent development has been that the leaders and members of the different movements are talking to and including each other, recognizing the commonalities between them and the issues they face.

The materials in this section emphasize the self-advocacy movement, which was organized by and for people with developmental disabilities, but the section includes materials produced by other groups as well.

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TITLE: Learning about self-advocacy series

AUTHOR: Crawley, B., Mills, J., Wertheimer, A., Whittaker, A., Williams, P., & Billis, J.

PUBLICATION INFORMATION: 1988

Campaign for Valued Futures with
People Who Have Learning Difficulties
12A Maddox Street
London, W1R 9PL
ENGLAND
Telephone: 01-491-0727

What is particularly important about self-advocacy is that it enables the empowerment of individuals who have been always spoken for. This five volume guide does this very effectively. Each of the five volumes begins with a "How to Use This Book" chapter. In this chapter, the authors encourage the individuals to use the book merely as support to the formation of their self-advocacy group, suggesting that the books be used based on the group's specific needs and to find answers to their specific problems.

Each of these books deals with an interesting array of topics. The first book discusses the meaning of self-advocacy and its uses and helps to create an awareness of an individual's rights and responsibilities in a free society. The other books deal with some of the issues of setting up an advocacy group and the organizational guidelines that are necessary for its efficient functioning. There are also suggestions on networking with other groups and on dealing with issues of publicity. One of the most important features of the last book is that is highlights particular skills in areas that facilitate group dynamics like communication, listening, being assertive, etc.

A particularly strong feature of this set of books is the simple language that is used to communicate its intent. Another strength is that it emphasizes that it is alright to ask people for help if one needs it, and offers a section on how to choose an advisor for the group who will not lead but empower. Each section in each book has a number of exercises and summaries of the important points. Also provided are a list of resources that could be used to complement the texts. In terms of a book that offers good suggestions, without being didactic, this book scores high.

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TITLE: Charting a bold course: A self-advocacy curriculum

AUTHOR: DeMerit, K. S., Halter, P. L., Jauron, G., Jirovetz, L., & Krueger, M.

PUBLICATION INFORMATION: 1988

Brown County Citizen Advocacy Program
Brown Association for Retarded Citizens
1675 Dousman, P.O. Box 10565
Green Bay, WI 54307-0567

This curriculum seeks to document some of the skills a self-advocate needs to possess in order to make informed vocational choices. In particular, this manual assists the individual in the decision making process, in using one's own value system to set realistic goals that are compatible with the professed values.

The curriculum is designed for a 12-week period of two sessions per week. There are several sessions that deal with specific goals. The first two sessions are intended to develop self-confidence and assist in strategies of self-assessment. This is followed by two more sessions on values clarification where individuals are encouraged to identify and prioritize personal values in order to make sound and reasonable value choices. Skills in decision making that call on reason rather than impulse or emotion are also included. The curriculum also deals with employment skills, confidence building in the face of interviews and answers questions on the "how's," "why's," and "when's" of both supported and community employment.

Looking at the comprehensive list of skills it endeavors to impart, this book does prove to be very useful. Not only does it provide session plans, it also includes handouts and questionnaires that complement the sessions. However, this book is very instructor-oriented and preserves in its own subtle way the service model. People using the book might want to pick and choose so as to de-emphasize this orientation.

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TITLE: The last civil rights movement: Disabled People's International

AUTHOR: Driedger, D.

PUBLICATION INFORMATION: 1989

St. Martin's Press, Inc.
175 Fifth Avenue
New York, NY 10010

The disability movement appears to be the last of the social movements of the 20th century. At least this is the claim made by Driedger in this book. Based on interviews, reports, letters and documents by those involved in Disabled People's International, Driedger argues that people with disabilities have a distinctive history that cannot be in accordance with viewing them as clients, patients or deviants dealt with by professionals.

Driedger articulates what the Disabled People's International (DPI) defines as a disability: the inability of the social environment in the community to accommodate to the needs of people who have limitations. She also points out that historically people with disabilities had little to say in any of the policies that are affecting their lives. In light of these philosophies, DPI was born as an organization "of" handicapped individuals rather than an organization "for" handicapped individuals. The book goes on to describe the history of DPI, the early years of struggle to get to be a group, and its goals and objectives.

One of the particularly redeeming features of this book is that it frankly voices the difficulties faced by an organization that claims to represent people with disabilities internationally. It lists the power politics among the "old boys" in the group, the elitism that often develops in leadership and the omission of people who are not powerful and who may have a voice in decision making. Of particular importance was the issue of people with disabilities in developing countries whose

extreme poverty and lack of resources often prevented them from participating in DPI sponsored events. Also mentioned are difficulties, political and otherwise, that affect an organization of international dimensions.

This book has inherent value in that it attempts a realistic portrayal of a self-advocacy organization with its warts and all. It also very effectively places the field of disability in the context of a social movement that can effect social change in the field of today.

TITLE: How to be an effective board member: Manual for self-advocates, manual for facilitators

AUTHOR: Eddy, B. A., Cohen, G. J., & Rinck, C.

PUBLICATION INFORMATION: 1989, December

University of Missouri-Kansas City
Institute for Human Development
2220 Holmes, Room 321
Kansas City, MO 64108

These two manuals are valuable additions to the sparse literature on how self-advocates can be effective as board members. The materials in these two manuals can be used to train self-advocates, or can be used directly by self-advocates who can read. The manual for self-advocates contains many drawings and pictures illustrating the text, which describes meetings, rules, board members' rights and duties (e.g. the right to ask for clarification, the right to voice an opinion, the duty to maintain order and sometimes confidentiality, etc.), and presents samples of board orientation materials. While the examples used are based on Kansas City or Missouri services and boards, the manuals would be useful to people in other states.

TITLE: We are People First: Our handicaps are secondary

AUTHOR: Edwards, J. P.

PUBLICATION INFORMATION: 1982

Ednick, Inc.
Box 3612
Portland, OR 97208

What happens when a group of former institution residents who are tired of being misrepresented and devalued decided to do something about this? They form a self-advocacy group: People First. We are People First describes the origin of the movement and its philosophy.

"People First" was started on January 8, 1974. Since then it has grown into a movement that has effectively articulated the needs of its members. The organization thus affords a chance to members to practice self-advocacy and self-assertion skills. A section of the book describes the early years, the difficulties, the conventions that were organized and the slow but steady growth of the organization into one of international dimensions. Some of the themes deemed important were the appreciation of help, the need and value for friends, pride in one's accomplishments and the negative effects of labeling. A section also describes how the members consider the role of the helper, a theme that today's self-advocates and professionals are still arguing about.

This book makes fascinating reading. It describes how individuals who were formerly dismissed as nobodies and interred in institutions have managed to fight back and articulate a strong message. Behind the obscuring handicap, is a person with dynamism and a vision to effect change.

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TITLE: The self-advocacy workbook

AUTHOR: Gardner, N. E. S.

PUBLICATION INFORMATION: 1980

Technical Assistance for Self-Advocacy Project
Kansas Center for Mental Retardation and
Human Development UAF
University of Kansas
Lawrence, KS 66045

This workbook provides a framework for learning about self-advocacy, organizing a group, and undertaking group action to deal with issues of common concern. The materials are specifically geared for use by a group. Each chapter attempts to focus on only one discrete aspect of organizing. Also, the structure of each presentation is the same throughout in order to minimize any problems the group might have with the management of their meetings.

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TITLE: Changing ourselves and our community: Report of a leadership development process with a self-help group in mental health

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1983

Family and Friends
Mental Health/Waterloo Region
179 King Street, South
Waterloo, ON N2J 1P7
CANADA

and

Centre for Research and Education
in the Human Services
P.O. Box 3036, Station C
Kitchener, ON N2G 4R5
CANADA

That leadership is important in self-help groups is undeniable. This book is an attempt to document a process of change for any self-help group. The purpose of this report is to highlight the unique nature of the leadership development process with a self-help group in mental health and also to raise questions, outline resources and suggest ideas useful to other groups concerned about change. Care has been taken to highlight that this is a "specific process" from which a linkage to "general principles" and issues can be made.

The report deals with the purpose of having self-help groups and the importance of creating a context where members can gain skills and knowledge and expand people's awareness of values, strategies and processes which would be helpful in impacting on mental health issues. There are also sessions included where members can be involved in planning and implementation through role playing, sharing and examining individual needs. Further, this book explores the process of change in the group and in the community in terms of identifying issues that need resolving and utilizing problem solving skills to address these issues.

TITLE: Whatever you decide

AUTHOR: Mohr, J.

PUBLICATION INFORMATION: 1983

Available from author:
Jennifer Mohr Johnson
238 Hampton Drive
Venice, CA 90291

Decision making is one issue that needs to be addressed when organizing a self-help group. This book is an example in this endeavor, in that it helps consumers be better prepared in the practice of decision making. This book is aimed at staff, educators and advocates and is geared to meet the needs of people at differing levels of comprehension.

The book first addresses the issue of the importance of teaching decision making skills. It also offers suggestions for forming groups, and various ways of improving group dynamics. Suggestions on how to choose an advocate and lead group discussions are also offered. A number of sample lessons pertaining to each topic are offered. This proves a good book for both advocates and self-advocates in the field.

TITLE: Speaking up and speaking out: An international self-advocacy movement

AUTHOR: People First of Washington, & Self-Advocacy Project, Rehabilitation Research and Training Center, University of Oregon

PUBLICATION INFORMATION: 1985

Ednick Communications
P.O. Box 3612
Portland, OR 97208

This self-advocacy booklet, perhaps the best resource on the various aspects of self-advocacy, is written for people with disabilities who have an interest in organizing or becoming part of a movement which advocates for their own rights and services. The roles of self-advocates and their advisors are clearly delineated in the booklet, but at the same time there is a recognition that each self-advocacy group will be unique.

The format of the booklet covers the planning and events of an international self-advocacy conference which was held by a group called People First (of Washington State). The conference participants share their experiences with words and pictures, providing a knowledge base to future self-advocates. Included throughout the volume are personal excerpts on people's thoughts and activities. The chapters cover basic issues such as describing self-advocacy, starting and supporting a local group, expectations about advisors, learning about self-advocacy, evaluating services, starting and supporting a state/province-wide organization, and other critical issues. An excellent resource.

TITLE: Self-determination

AUTHOR: Perske, R. (Ed.)

PUBLICATION INFORMATION: 1989

Institute on Community Integration
6 Pattee Hall, University of Minnesota
150 Pillsbury Drive, Southeast
Minneapolis, Minnesota 55455

This is a summary of the proceedings of a national conference on self-determination to which sixty people were invited by the Office of Special Education and Rehabilitative Services, U.S. Department of Education. Over half the planners have disabilities of one kind or another. This was a first: people with disabilities, parents, and close supporters being asked to draft specific recommendations for federal officials regarding future directions for people with disabilities. This booklet presents their recommendations, some viewpoints of people at the meeting, and each of the keynote presentations.

TITLE: How we lived and grew together: An interstate seminar on self-advocacy for persons with developmental disabilities

AUTHOR: Perske, R., & Williams, R.

PUBLICATION INFORMATION: 1984

InterServ
Clarence York, President
39 East 51st Street
New York, NY 10022

This is a report on the proceedings of a conference on self-advocacy for people with developmental disabilities. Some of the topics dealt with in this conference were the nature of meaningful work and participation in community activities, consumer empowerment and the effects of attitudes of the community and labelling by professionals of people with developmental disabilities. The booklet has several quotes from several government officials as well as from many program participants.

TITLE: People with developmental disabilities speak out on quality of life: A statewide agenda for enhancing the quality of life of people with disabilities

AUTHOR: Vivona, V., & Kaplan, D.

PUBLICATION INFORMATION: 1990, March

World Institute on Disability
510 16th Street
Oakland, CA 94612
(415) 763-4100

This booklet provides a description of the World Institute on Disability's Quality of Life Project, a project that culminated in a series of conferences in which people with developmental disabilities discussed and made recommendations related to four areas: working, living, loving, and playing. Their recommendations are incorporated in the booklet, as are several appendices that would be helpful to those wishing to put on similar conferences.

TITLE: We can speak for ourselves: Self-advocacy for mentally handicapped people

AUTHOR: Williams, P., & Shoultz, B.

PUBLICATION INFORMATION: 1984

Brookline Books
P.O. Box 1046
Cambridge, MA 02238
(617) 868-0360

This book tells the story of People First of Oregon, Project 2 of Nebraska, and similar efforts in England where participants have been building the skills necessary to take charge of their own lives. The book offers practical advice and support for parents, human service workers, and others interested in assisting self-advocacy for mentally handicapped people. It includes detailed descriptions of several organizations, lists teaching materials, and presents personal accounts by participants in self-advocacy groups both in the United States and in England. This book is also a valuable resource to sensitize the direct service worker, the administrator, and the public official to the importance of self-advocacy.

ADVOCACY

Of the many books and chapters on advocacy, we concentrate here on materials that can be used by and on behalf of people interested in change, including those with disabilities. These materials present "nuts and bolts" suggestions as well as indepth examinations of laws, governmental programs, and needed improvements. Of course, materials annotated in other sections should also be useful in developing a vision for advocacy (e.g., "Planning with Individuals," "Self-Advocacy," "Families," "Community Living," "Acceptance, Relationships, and Community" and so on). The section also includes two personal stories, one by a parent and one by a professional, that illustrate advocacy at its best, and an article by a man with a disability expressing his and others' need for the support of advocates or allies.

TITLE: Let our children go: An organizing manual for advocates and parents

AUTHOR: Biklen, D.

PUBLICATION INFORMATION: 1974

Human Policy Press
P. O. Box 127
University Station
Syracuse, NY 13210

COST: $4.50 plus $1.50 minimum shipping and handling

This book describes how parents of children with disabilities, and their allies, can fight for their own needs and rights. If you question why some children have been sent off to remote institutions, or why so few children with disabilities attend day care centers and regular public schools, or why special classes are often placed in school basements or in "special" isolated schools, then this book is for you. If you are an advocate for change, you can use this book as a manual for action. Advocacy means moving bureaucracies. This book describes how to do it--the basic steps to successful organizing.

TITLE: Principles of whistleblowing

AUTHOR: Biklen, D., & Baker, M.

PUBLICATION INFORMATION: 1979

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $.65 plus 10% shipping and handling

This article provides a clear understanding of why whistleblowing needs to occur. It offers guidelines that help prioritize the most effective steps for carrying out this task. It is a tool which could be used to expose illegal, immoral and otherwise wrong practices in human services, business, government and other organizational settings.

TITLE: Rights and reality: An action guide to the rights of people with disabilities in Wisconsin

AUTHOR: Breedlove, L., Franz, J., Froemming, R., Greenley, D., & Marker, J.

PUBLICATION INFORMATION: 1986

Wisconsin Coalition for Advocacy
16 North Carroll, Suite 400
Madison, WI 53703

Wisconsin has long had state (some federally-funded) programs that encourage individualization in services and funding. This manual attempts to provide the reader with a basic understanding of state and federal laws which apply to Wisconsin residents who have physical or mental disabilities. It should be helpful to individuals wishing to advocate for their own rights, or the rights of others. It was also written as an informational guide about the rights of people with disabilities. Brief legal citations that are included may make it useful for lawyers.

This manual is based on the three values concepts of maximizing independence, consumerism and the consumer movement, and the normalization principle. It includes chapters on SSI, Medical Assistance, Medicare, Chapter 51, Protective Services, Civil Commitment, Guardianship, Section 504, Rights in Institutions, Vocational Rehabilitation, the Child Welfare System, and several Wisconsin programs of interest to advocates of individualization.

Although the federal entries may be useful to people from other states, this manual is written from Wisconsin's state law perspective. It is a comprehensive and clearly written assessment of their resources and practices, and useful to anyone wishing to understand better some of the innovative Wisconsin programs and structures.

TITLE: Annie's coming out

AUTHOR: Crossley, R., & McDonald, A.

PUBLICATION INFORMATION: 1984

Penguin Books Ltd.
Viking Penguin Inc.
40 West 23rd Street
New York, NY 10010

This is the truly remarkable and moving true story of Anne McDonald who, because of severe cerebral palsy, spent fifteen years in an institution, St. Nicholas Hospital for children in Melbourne, Australia, and Rosemary Crossley, who worked as an assistant to the hospital psychiatrist, and the long battle they fought against an obdurate bureaucracy to stop the incarceration of severely handicapped youngsters on grounds of incompetence and infirmity.

Anne describes her struggle to survive against all odds and indignities in an environment that believed her to be "non-human" and incapable of any communication, and her excitement when Rosemary recognized her ability and showed her an alternative, nonverbal means of communication that opened up a new world for her. Staking her job and professional reputation to get Anne and a handful of other young people out of St. Nicholas, Rosemary describes the many hours spent trying to convince unbelieving hospital and court officials that Anne is capable of independent thought, the problems encountered and overcome as Anne makes her first attempt at living outside the institution, the setbacks and the victories that finally led to the closing of St. Nicholas Hospital.

It is a story that will inspire and give renewed hope to advocates, parents and professionals and to those who believe that all people deserve to live with dignity.

TITLE: Unraveling the special education maze: An action guide for parents

AUTHOR: Cutler, B. C.

PUBLICATION INFORMATION: 1981

Research Press Company
P.O. Box 3177
Champaign, IL 61821

As its title suggests, Unraveling the special education maze is a book about how parents can effectively work with and advocate in schools to improve the quality of programming for their children. Barbara Coyne Cutler, a parent, has long been an activist on behalf of children's rights. She brings a wealth of experience and examples to the text.

In addition though, and perhaps more important, this book speaks to the issue of parent attitudes in a manner few other works have come close to accomplishing. Cutler describes how parents feel when they approach schools. She gives us an accounting of "good" and "not so good" ways in which school personnel treat families. This is a book filled with humor, commitment, and lots of food for consciousness raising. This book has been particularly popular with parents and, I suspect, with administrators as well. It has a lot to teach us all.

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TITLE: How to organize an effective parent/advocacy group and move bureaucracies

and

How to get services by being assertive

AUTHOR: Des Jardins, C.

PUBLICATION INFORMATION: 1980

Coordinating Council for Handicapped Children
408 South Dearborn, Room 680
Chicago, IL 60605

Both of these handbooks serve to guide the reader through advocacy issues. They were specifically written for parents and siblings of children with disabilities, but they are generalizable to any situation that calls for advocacy in order to obtain necessary services.

The handbooks are instructive and deal with the "how to's" of organizing advocacy efforts. They also are written with a strong amount of encouragement to get involved in the issues which face the reader or his/her relative. The tone of these handbooks is that of an assertiveness workshop, and they tend to be oriented toward women who are relatively inexperienced in speaking out for what they believe.

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TITLE: Disability rights guide: Practical solutions to problems affecting people with disabilities

AUTHOR: Goldman, C. D.

PUBLICATION INFORMATION: 1987

Media Publishing
2440 "O" Street, Suite 202
Lincoln, NE 68510-1125

This book is intended for use by all persons who deal with the important human issues confronted by persons with physical or mental limitations. Chapter One focuses on Attitudinal Barriers and demystifies some of the generally accepted misconceptions regarding people with disabilities (e.g., disability is inability). Outlined in the following chapters are employment, accessibility, housing, education, and transportation. In reference to each of these issues, state, federal, and local laws are highlighted and practical solutions to these problems are suggested in each chapter.

Also included are three appendixes: Appendix I: State by State Guide: Laws & Contacts; Appendix II: Federal Contacts; and Appendix III: A.I.D.S.

TITLE: ACTION: A manual to help you organize

AUTHOR: Governor's Planning Council on Developmental Disabilities

PUBLICATION INFORMATION: 1989

Governor's Planning Council on
Developmental Disabilities
Minnesota State Planning Agency
300 Centennial Building
658 Cedar Street
St. Paul, MN 55155
(612) 296-4018
(612) 296-9962 TDD

This handbook is designed to offer some common-sense tactics for consumer advocates to use in achieving their goals. It explains the strength gained by organizing and knowing your allies. Listed are specific sources of background material and where to obtain them. It explains writing techniques and provides a sample questionnaire, and has copies of petitions and letters to aid in canvassing and developing new support for your group. There is much valuable information on how to meet with officials in person and on public speaking. This clearly written manual offers many

suggestions and would prove an asset to any group or individual desiring to organize effectively.

Copies are available free of charge by contacting the above address or telephone number.

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TITLE: The future of advocacy for persons with mental disabilities

AUTHOR: Herr, S. S.

PUBLICATION INFORMATION: 1987

Rutgers Law Review, Winter/Spring 1987, 39(2/3).

The introduction to this article focuses on the evolution of the American movement to provide advocacy services for people with mental disabilities. Its main theme is the discussion of the need to assure people access to qualified advocates who can aid in the understanding and implementation of mental disability law. Along with describing the need for advocacy services, this article considers the availability of such advocates, analyzes several advocacy models and outlines several critical challenges whose resolution will determine the future of this field.

The advocacy models analyzed include legal advocacy, self-advocacy, lay advocacy, friend advocacy, human rights committees, and internal rights protection functions that designate staff members to be "rights advisors."

In the development of an integrated and comprehensive advocacy network, the author emphasizes outreach activities, the right of access to the courts, and sources of public funding for advocacy assistance.

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TITLE: Rights and advocacy for retarded people

AUTHOR: Herr, S. S.

PUBLICATION INFORMATION: 1983

Lexington Books
D.C. Heath and Company
Lexington, MA

This text chronicles judicial activity during the second half of the twentieth century. It is a comprehensive review that reflects on the multitude of legal developments from a variety of perspectives--historical, international, and policy-oriented--that help explain the growing awareness of the need to enforce human and legal rights for individuals with a mental disability.

It examines the legal frameworks that perpetuated the residential segregation of people with mental retardation. It considers to what extent lawmakers can undo this history of segregation and delineates the legal directions and safeguards that offer a brighter future. Changes in due process now give clients and their representatives the right to object to care and treatment received. Though the rights to care, habilitation, and education exist, the means of their delivery are confused and often ill-conceived. This is why legal advocates must continue to gain support for their complex agenda: diligent monitoring of resettlement efforts, a wide range of choices of living arrangements and services of intimate scale and high quality, and more comprehensive legal reform.

The author strongly speaks out in favor of the advocacy movement for those who are too young, too incapacitated or too vulnerable to act alone. He defines and discusses the many types of advocacy that are available to assure these individuals' rights.

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TITLE: Organizing--A guide for grassroots leaders

AUTHOR: Kahn, S.

PUBLICATION INFORMATION: 1982

McGraw-Hill Book Company
1221 Avenue of the Americas
New York, NY 10020

This book is a comprehensive, clearly written resource that explains the benefits of organizing as well as where and how to start. It offers insight into building organizations, identifying constituencies, selecting leaders and encouraging membership. It provides specific tactics for carrying out the strategies that your organization develops based on the goals of the group. Also addressed are media contacts and the advantages and disadvantages of including the media in various communication strategies of the organization. Money management and coalition building are two other areas that the book highlights.

This reference tool is valuable to both individuals who want to start a new group and leaders of established organizations.

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TITLE: Training exercises for human rights committee volunteers

AUTHOR: Laski, F., & Piccoli, M.

PUBLICATION INFORMATION: 1984

Community Human Rights Committee Project
Developmental Disabilities Center
Temple University
Ritter Hall Annex, 9th floor
Philadelphia, PA 19122

This manual is based on training programs conducted by the Human Rights Committee Project Staff. It is directed at volunteers who have already received substantive training or who have experience working in human services for people with developmental disabilities.

A human rights committee generally oversee the behavior management and medication programs of an agency. In this role, it is a watchdog that monitors agency practices and ensures individuals' rights.

This manual discusses some specific issues of individual rights that surfaced during their brainstorming session. After a discussion of Behavior Modification and Policy issues, there are exercises in medications policy and individual complaint hearings.

Although this is geared toward people of some experience, there is a wealth of information presented in a clearly organized structure. It provides an understanding of the role and activities of the human rights committees. Also included are various copies of letter styles, and reports and forms used in records of individuals.

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TITLE: Toward independence: An assessment of federal laws and programs affecting persons with disabilities--with legislative recommendations

AUTHOR: National Council on the Handicapped

PUBLICATION INFORMATION: 1986

National Council on the Handicapped
800 Independence Avenue, S.W.
Suite 814
Washington, DC 20591
(202) 453-3846 (voice or TTY)

Although the nation's goals regarding citizens with disabilities have often been stated. Federal programs and laws have often deviated from the paths leading to these goals. This report results from Congress' direction to the National Council on the Handicapped to assess Federal programs to determine the extent to which they achieve the following: a) provide incentives or disincentives to the establishment of community-based services for individuals with disabilities; b) promote the full integration of such individuals in the community, in the schools, and in the workplace; and c) contribute to the independence and dignity of such individuals.

Contained within this report are some very revealing statistics about the ten major topic areas isolated for assessment. These topic areas are: Equal Opportunity

Laws, Employment, Disincentives to Work Under Social Security Laws, Prevention of Disabilities, Transportation, Community-Based Services for Independent Living, Housing, Educating Children with Disabilities, Coordination, and Personal Assistance: Attendant Services, Readers, Interpreters.

The major conclusions and legislative recommendations of the Council regarding these areas are included in this report.

TITLE: Sticks and stones: The story of loving a child

AUTHOR: Pieper, E.

PUBLICATION INFORMATION: 1977

Human Policy Press
P.O. Box 127
University Station
Syracuse, NY 13210

COST: $4.50 plus $1.50 minimum shipping and handling

This book provides many examples of parent advocacy as it tells the story of Jeff Pieper and his family's life with him. Jeff was almost universally "written off" by professionals, especially doctors and school administrators, who seemed not to care whether he lived or died. His family and his community, on the other hand, saw him as valuable and worth the work and struggles they went through to give him a chance. Betty Pieper's story communicates as much about our society as it does about the Pieper family. She writes with warmth, determination, and anger.

Like most new mothers, Betty Pieper knew little about disabilities when her son was born. Choosing to love him, she quickly encountered the many ways in which our society discriminates against people with disabilities, and she also learned how to advocate for him and for all people with disabilities. This is a wonderful book by a mother who is also an effective agent for change and a good writer.

TITLE: SSI and Social Security Disability: Securing and protecting your benefits

AUTHOR: Protection and Advocacy, Inc.

PUBLICATION INFORMATION: 1989, January

Protection and Advocacy, Inc.
175 West Jackson Boulevard
Chicago, IL 60604

This self-advocacy guide was prepared for the use of persons who have a disability. It will also be useful to family members, attorneys, advocates, health and social service professionals, and other persons interested in public benefits. It discusses specific social security programs that are available to persons with disabilities. The handbook lists general eligibility requirements and references for what agencies to contact for more detailed information. It also discusses the application process, the eligibility decision, the appeal process, review and termination of benefits and work incentive programs.

Protection and Advocacy, Inc. would like to make this handbook accessible to all persons and is willing to provide it in the form of cassette tapes or in another language.

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TITLE: Strategies: A practical guide for dealing with professionals and human service systems

AUTHOR: Shields, C. V.

PUBLICATION INFORMATION: 1987

Human Services Press
P.O. Box 421
Richmond Hill, ON L4C 4Y8
CANADA

Parent-professional interactions don't always have to be confrontational. This "how to" book candidly appraises the ways that many professionals within the system of human services often can become combative with parents of disabled children, and tells parents how to be effective in their role of advocate for their child by converting confrontational situations into cooperative ones instead.

The book is simply written, uses no jargon, and offers practical tips. When access to a professional or to information is difficult, it is useful to know "the system," to be able to distinguish between professional objectivity and professional indifference, to know what one's rights are and how to apply pressure, if necessary. Basing itself on the understanding that to require special services is a normal, acceptable need and not a sign of inadequacy, it exhorts parents to be well-informed, to stay involved, and to participate. An extensive list of major support groups for parents is included.

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TITLE: Negotiation: A tool for change

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1979

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $.65 plus 10% shipping and handling

This paper is designed to enable consumers, parents and advocates to negotiate effectively, whether it is for short or long-term change. It concisely outlines steps for general negotiation preparation such as knowing when to negotiate, obtaining backing by a consumer or interest group, setting up the negotiation, targeting agency heads/persons with authority, organizing meetings, forming a negotiating team and preparation for the actual negotiation. It also lists strategies for effective negotiation and follow-up techniques.

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TITLE: You've got a friend

AUTHOR: Worth, P.

PUBLICATION INFORMATION:

In The pursuit of leisure: Enriching the lives of people who have a disability.

The G. Allan Roeher Institute
York University, Kinsmen Building
4700 Keele Street
Downsview, ON M3J 1P3
CANADA

This chapter comes from a book entitled The pursuit of leisure. The honesty of Pat Worth's account of how people with disabilities are trapped without the support of advocates is moving. It is a truly personal perspective on the need for advocates to aid persons with disabilities in their quest for freedom and choice.

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FAMILIES

Over the past forty years, the families of children and adults with disabilities have been a tremendously important force for positive changes in services for people with disabilities. In the past decade, the research and the materials by and about families have "caught up" with the outlook and perspectives many families have always had. The books reviewed in this section are positive about and helpful to families who have one or more family members with disabilities, as well as to professionals and others interested in families. For materials specifically addressing ethnically and culturally diverse families, see the "Perspectives" and "Planning and Coordination of Services" sections.

TITLE: Enabling and empowering families: Principles and guidelines for practice

AUTHOR: Dunst, C., Trivette, C., & Deal, A.

PUBLICATION INFORMATION: 1988

Brookline Books
P.O. Box 1046
Cambridge, MA 02238

In contrast to much of the literature and practice focussing on family deficits, this book presents an alternative conceptualization of families and a new approach to early intervention. The "enablement" or "empowerment" approach explores four themes: 1) the entire family should be the focus of intervention; 2) family needs should be met in such a way that family competence is increased; 3) practitioners must believe that parents have the right to determine their family's course of development; and 4) positive family functioning should be recognized and promoted. This book will be especially helpful for early intervention specialists but will also be helpful for anyone working with families.

TITLE: A difference in the family: Life with a disabled child

AUTHOR: Featherstone, H.

PUBLICATION INFORMATION: 1980

Basic Books, Inc.
New York, NY

Having a child with severe disabilities, says the author, makes a difference in the family. At first, willy-nilly, the child is a dominant motif. But in time, the family becomes accustomed to the situation and gradually returns to the mainstream. Born out of her own experience as the mother of a boy with multiple handicaps, this book is about how it feels to belong to a family with a disabled child.

The book uses three sources of information: the author's own experience, personal interviews conducted by the author with other families, and a well-researched body of literature written by parents on their experiences. Chapters deal individually with fear, anger, loneliness, guilt and self-doubt, and acceptance, as the book describes the emotional stages the family goes through as it learns to live with a disabled child. Other concerns are marital stress, siblings, giving and getting help. A particularly useful resource for professionals working with families, the book provides an insightful analysis into the many ways the presence of a child with disabilities changes the structure of the family.

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TITLE: Families of handicapped children: Needs and supports across the life span

AUTHOR: Fewell, R. R., & Vadasy, P. F. (Eds.)

PUBLICATION INFORMATION: 1986

Pro-Ed
5341 Industrial Oaks Boulevard
Austin, TX 78735

Several features of this book make it unusual and interesting to read. The use of an ecological and sociological framework of analysis to explain the reciprocity of familial relationships helps us understand how different members, disabled and nondisabled, can impact upon each other. The authors also employ a life span approach which acknowledges the present and potential impact and needs of family members at varying stages of their lives. Most significantly, it presents the hitherto little-known perspectives of siblings, fathers, grandparents and single mothers of children with disabilities. This is done by using extensive quotes, by including articles written by family members, and stories or experiences related by them.

The book also deals with the impact of other environments on the family. Public school, social networks, church and community all have a part to play in the life of people. The impact these environments can have on children with disabilities and their families, how roles are redefined, and how families can and do cope, is discussed. This is recommended reading for professionals, who may better appreciate

how a handicap can affect the ecology of a family, and for parents, who may learn of the educational and community supports which address the special needs of the child and the family.

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TITLE: The power of positive linking: How families can empower people who have a mental handicap through mutual support groups

AUTHOR: The G. Allan Roeher Institute

PUBLICATION INFORMATION: 1989

The G. Allan Roeher Institute
Kinsmen Building, York University
4700 Keele Street
Downsview, ON M3J 1P3
CANADA

This study documents the evolution of five support groups across Canada. Each group was made up of families with a disabled member who came together during times of crisis and/or trying to identify more opportunities for their family members with disabilities. Through in-depth interviews, the experiences of these mutual support groups were collected. The study describes how the five support groups were established, the meaning, process, and goals of "support," and the internal functioning of the groups over time. How the support groups established ties to other groups and agencies in order to obtain needed resources to meet their goals is also discussed.

While the title suggests otherwise, this study really explores the empowerment of the families through the mutual support groups.

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TITLE: Meeting the challenge of disability or chronic illness - A family guide

AUTHOR: Goldfarb, L. A., Brotherson, M. J., Summers, J. A., & Turnbull, A. P.

PUBLICATION INFORMATION: 1986

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book is an extremely unique and valuable tool, written for all families experiencing any type of situation involving care of an ill or disabled family member. It is also an important resource for professionals working with families. Filled with

practical worksheets, activities and exercises, it provides information and techniques for family members to utilize in coping with their particular situation.

Part I, "Taking Stock," discusses methods of coping, relying on one's value system, and various types of social and professional support. Part II, "Problem Solving," deals with family communication, problem definition, brainstorming for solutions, evaluation of alternatives, and action toward solving problems. The authors also include an Appendix of Resources, which contains a number of bibliographies on various subjects and a list of support organizations.

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TITLE: As up we grew with Barbara

AUTHOR: Moise, L. E.

PUBLICATION INFORMATION: 1980

TASH
7010 Roosevelt Way, N.E.
Seattle, WA 98115

This book belongs to an important genre of first-person accounts by parents who, after becoming activists in the parent movement, wrote about their experiences. Many of these parents, who are now in their sixties or seventies, paved the way for today's strong parent movement. This book is a very personal description of the Moise family's life with Barbara, the child with the disability, and of the family's suffering and growth as they encountered inexpert and insensitive professionals, inadequate services, societal rejection, and the realization that these were not the family's fault but instead the result of a social injustice that could be resisted. This book describes Barbara's growth, but it also traces the author's transformation from parent to activist, and discusses many issues rising out of the transformation. (There are many books that belong to this genre, and that will not be annotated here for space reasons. Feel free, however, to write or call the Center on Human Policy for other titles.)

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TITLE: Hope for the families: New directions for parents of persons with retardation or other disabilities

AUTHOR: Perske, R. (Illustrated by M. Perske)

PUBLICATION INFORMATION: 1981

Abingdon Press
201 Eighth Avenue, South
P.O. Box 801
Nashville, TN 37202

As the author says, "this book is for families who are trying to turn a tough situation into a rich experience." This is one of THE books for families in which one of the members has a disability. In 28 brief up-beat chapters, the author confronts and exorcises the ghosts which our culture imposes on people with disabilities and their families. He shows many ways parents and families can overcome their fears and inhibitions. Some of the wide-ranging topics discussed include: changing world views, theology, human dignity, sexual development, family systems, and opening opportunities for persons with retardation and other disabilities. To clarify his meaning, draw out his implications and encourage discussion, the author concludes most chapters with mini-"home"-work assignments entitled "Consider these options." The marvelous illustrations re-double the impact of this impressive little book.

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TITLE: Parent to parent

AUTHOR: Pizzo, P.

PUBLICATION INFORMATION: 1983

Beacon Press
25 Beacon Street
Boston, MA 02108

This book is about parent self-help and advocacy, and discusses the ways in which parents facing all sorts of problems, ranging from loss of a child due to drunk driving to abusiveness toward their children to having a child with a disability, have come together to help and get support from parents facing similar problems. The author discusses ways in which people sharing the same experience can empower each other, gives a history of parent activism, discusses and debunks commonly held stereotypes of parents, and gives a myriad of examples of ways parent power has changed laws, services, and attitudes. This book is useful for several reasons--it gives a history of a number of parent-initiated movements (black single parents, parents of children with disabilities, etc.), showing how the issues they face and the forces to which they have responded may have common sources; it describes women activists in all these movements; and it lists parent self-help and advocacy organizations.

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TITLE: After the tears: Parents talk about raising a child with a disability

AUTHOR: Simons, R.

PUBLICATION INFORMATION: 1987

Harcourt Brace Jovanovich
Publishers
1250 Sixth Avenue
San Diego, CA 92101

Like most books that deal with parents' perspectives on disability, this book describes the emotional stages that parents go through on learning of their child's disability. What makes it a book to be recommended is that it also describes how parents have coped through these stages.

The book is very readable, being slim with short chapters that contain extensive quotes by parents. It legitimizes as being normal the strong emotions of anger and guilt that parents may experience. It accepts that some of the consequences of having a disabled child may have to do with the awkwardness of dealing with marital stress, relatives, siblings, professionals, and worries about the future. But unlike most other books, this book goes beyond and offers solutions arrived at by parents themselves for those situations most commonly encountered (for example, architectural barriers, the school system, curious strangers) while recognizing the fact that solutions are not universally applicable and would of necessity, differ according to the circumstances of each family.

Each chapter closes with simple and practical suggestions for developing coping strategies. The last chapter lists some resources on information and referral services, health care, legal aid, advocacy, books, publications, directories and films.

TITLE: Families, professionals, and exceptionality: A special partnership (Second ed.)

AUTHOR: Turnbull, A. P., & Turnbull, H. R.

PUBLICATION INFORMATION: 1990

Macmillan Publishing Co.
Front & Brown Streets
Riverside, NJ 08075

or

Merrill Publishing Co.
1300 Alum Creek Drive
Columbus, OH 43216

This book, which can be used as a textbook for students training to become professionals, will also be of interest to those who are currently professionals and to family members. It is value-based, in that it identifies six core values about people

with disabilities and their families and points out ways throughout the book to incorporate these values into professional practice. This edition emphasizes the application of family-systems theory in professional practice, taking into account the variety and diversity in families and the various life cycle stages families generally pass through.

The chapters explore the historical and current roles of parents, family characteristics, family interaction, family functions, family life cycle, communication skills for professionals, strategies for communication, P.L. 94-142, various aspects of family involvement and legal issues, ways of supporting families and helping them cope, and professional ethics and morals. The book presents positive ways of understanding and working with families, giving many examples and quoting many parents. The points of view of family members in many different situations are presented, so that the reader comes away with a feeling of having met and talked frankly with many parents, siblings, and extended family members. The chapter on ethics and morals is replete with case examples that present moral or ethical conflicts as well as succinct descriptions of sources of moral principles for students to consider. Throughout, the book provides references and data to back up the content, and includes an extensive reference list and two appendices (resources for families and professionals and a guide for gathering family information through discussion) at the end.

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TITLE: Parents speak out: Then and now

AUTHOR: Turnbull, H. R., & Turnbull, A. P. (Eds.)

PUBLICATION INFORMATION: 1985

Charles E. Merrill Publishing Co.
1300 Alum Creek Drive
Columbia, OH 43216

This book is a collection of essays by parents (twelve mothers, seven fathers) and a few brothers and sisters of people with disabilities. Many of the authors are leaders in the parent movement, and a number have qualifications as professionals in some aspect of the health or disability field. Some of the essays by professionals reflect on the difference in perspective when one is in the parent role and dealing with the professionals who exercise power over the services one's child receives. Many of the essays are passionate, describing the personal feelings of the authors in parenting a child with disabilities and dealing with societal and professional pressures and prejudices. A classic in the "parent" literature.

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TITLE: Disability and the family: A guide to decisions for adulthood

AUTHOR: Turnbull, H. R., Turnbull, A. P., Bronicki, G. J., Summers, J. A., & Roeder-Gordon, C.

PUBLICATION INFORMATION: 1989

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

This book is a planning guide for families who have one or more members with disabilities. It specifically emphasizes the period of transition to adulthood, but can be used by any family wishing to consider alternatives for a disabled family member. The book provides a wealth of help and information for families thinking about the future. such as a "preference checklist" that helps families determine the preferred supports and services their family member will need. There are two chapters on advocacy that encourage parents to speak out vigorously within existing services for what their child needs or to participate in creating new services if existing services are unresponsive.

These two chapters assume that the family members have made explicit their needs and dreams for the person with the disability, and have decided, together with that person, what the future for that person should look like. They also assume that many of the actual services the person and the family may encounter will fall far short of the picture they have created, and that families must find ways of causing change to meet their family members' needs.

ACCEPTANCE, RELATIONSHIPS, AND COMMUNITY

Almost all people need to feel that they belong and have meaningful relationships with others. Unfortunately, much of the literature reflects a belief that communities and the people in them are unable and unwilling to welcome people with developmental disabilities into their midst. There are studies on loneliness and isolation, courses on the sociology of deviance, and workshops and books on ways of overcoming community resistance.

The materials in this section reflect a more positive way of thinking. They look at accepting relationships and responsive communities, and examine some of the dynamics that underlie these phenomena. They propose changes, not just in "the community," but in ourselves. In what ways have we--service providers, professionals, advocates--created the barriers we talk about? How can we best promote and support caring relationships and community participation? These materials attempt to address these issues at several levels.

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TITLE: The social basis of community care

AUTHOR: Bulmer, M.

PUBLICATION INFORMATION: 1987

Allen & Unwin, Inc.
8 Winchester Place
Winchester, MA 01890

This book analyzes the relationship between ideas about community life and the impact of social policy, demonstrating that, at least in England, there is "a vacuum at the heart of care policy which is likely to lead to ineffective or deteriorating provision of services" (p. ix). Bulmer's analysis is very relevant to North American discussions about community integration of people with disabilities. The book focuses more on informal support or care than on services and service systems, but he looks at both and at the interface between the two types of care in the community. His analysis draws heavily on a variety of research studies conducted in neighborhoods, within groups of families, and in other aspects of community life and is a major contribution to the discussion about community integration.

This book is addressed to academics and policy makers.

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TITLE: It's about relationships

AUTHOR: Forest, M.

PUBLICATION INFORMATION: 1989

Frontier College Press
35 Jackes Avenue
Toronto, Ontario M4T 1E2
CANADA

This essay is also a chapter in L. Meyer, C. Peck and L. Brown, Critical issues in the lives of people with disabilities, (1990), Paul Brookes Publishing Company. It

is a personal reflection by Marsha Forest on the many relationships that have enriched her life and the lives of her friends and family members. Interwoven with the personal stories are stories about integrating students with disabilities into regular schools. Always, Forest points out how much we all have to give each other, and how much we miss when people with perceived differences are excluded from schools, neighborhoods, and friendship circles.

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TITLE: The Joshua Committee: An advocacy model

AUTHORS: Forest, M., & Snow, J.

PUBLICATION INFORMATION: 1983, Winter

The Journal of Leisurability, 10(1).

TITLE: Friends circle to save a life

AUTHOR: Perske, R.

PUBLICATION INFORMATION: 1988, January

TASH Newsletter, 14(1).

TITLE: Friends circle to save a life

AUTHOR: Perske, R.

PUBLICATION INFORMATION: 1988, March

Augustus: A Journal of Progressive Human Services, XI(3).

In these three articles, the authors document the life of Judith Snow, a Canadian woman who has extensive physical disabilities. Although well educated and employed at York University, Ms. Snow was forced to live in a nursing home in order to receive the physical assistance that she needed. Through the combined efforts of several of her friends, Snow was enabled to leave the nursing home and move into her own apartment.

Forest and Snow share the insider's view of this story while Perske brings us up-to-date with the events of the past five years.

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TITLE: Everyone here spoke sign language

AUTHOR: Groce, N. E.

PUBLICATION INFORMATION: 1985

Harvard University Press
79 Garden Street
Cambridge, MA 02138

This ethno-historical study is an excellent portrayal of community life for deaf and hearing individuals of Martha's Vineyard. The reader is presented with the history of how the deafness was brought to the island. The book allows the reader to view the typicality of the lives of Islanders who were deaf, typicality due to the community's acceptance that deaf and hearing individuals were all community members. Those who could hear learned sign language so that communication could occur. Groce takes us beyond the confines of medical or social definitions of deviancy and offers evidence that our pre-concieved stereotypes of what a disability may mean is really determined by the social construct we create as a society.

This well-researched book is a must, not only for people interested in the field of disabilities but for anyone trying to struggle with integration into community life. The book contains a simple thesis offering a profound message in a wide area of disciplines. It will add thought to issues that will remain unresolved and discussed for a long time to come.

TITLE: Understanding social networks

AUTHOR: Lambert, M.

PUBLICATION INFORMATION: 1983

Sage Publications
275 South Beverly Drive
Beverly Hills, CA 90212

This book pursues the increasing popularity of the concept of social networks in the human services field by offering the reader an organized and concise view not only of what networks are, but how they can be organized around individuals, groups, communities and organizations as a means to empower individuals.

First, the idea of networking is placed within its rich historical context which helps in demonstrating its well established value. As well as defined networking, its usage as a means of self-help and mutual aid are addressed. A common theme is that networks, when developed, will form a common chain and the networker will become

the linkage connecting people to each other rather than relying on only the social services workers or agencies.

An idea that was addressed in the book but needs closer consideration in general is that of establishing natural networks with and for people. The book is a good over-all guide for those interested in looking at services beyond the service system and in need of some tools for how to go about initiating such a process.

. . . . . .

TITLE: Creating responsive communities: Reflections on a process of social change

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1985

OAMR
1376 Bayview Avenue
Toronto, Ontario M4G 3A3
CANADA

A clear and concise look into one province's struggle in attempting to create a responsive community, this study addresses the idea that, by themselves, more rights and services for people with disabilities and their families are not enough, and that physical presence alone does not mean inclusion. True involvement within the community, it concludes, means necessary supports to allow full participation and opportunities for friendships.

The report focuses not only on lessons related to the emerging vision and strategies this organization used in promoting a sense of community, but also on some of the problems they encountered. A strong family and community emphasis is clear throughout the book, as well as the strength of advocacy in creating such environments. Self-advocacy is mentioned, also, but to a lesser degree. While much of the book deals with the historical development of the province's approach, some interesting and currently relevant principles are set forth in a chapter on assistance to individuals and families.

. . . . . .

TITLE: Affectionate bonds: What we can learn by listening to friends

AUTHOR: Lutfiyya, Z. M.

PUBLICATION INFORMATION: 1990

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $4.35 plus 10% shipping and handling

In this monograph, Zana Lutfiyya describes a qualitative study conducted with four pairs of friends in the Syracuse area. In each of these pairs, one person has a disability label and one does not. The author offers perspectives on friendship found in the literature, describes each of her informants and their friendships, explores the dimensions and characteristics of friendship, and relates the rights, responsibilities and obligations of friendship in her informants' eyes. She discusses how some friendships move toward greater intimacy while others stay the same or die away, and lays out some of the implications of her study for the human service world, for families, and for people thinking about their own friendships. This ground-breaking study should begin to focus our thinking on what really goes on in friendships, including those between people with and without disabilities.

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TITLE: Reflections on relationships between people with disabilities and typical people

AUTHOR: Lutfiyya, Z. M.

PUBLICATION INFORMATION: 1988

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $1.90 plus 10% shipping and handling
(for full information package)

This article is part of a larger information package on relationships prepared by the author in 1988 in response to requests for inforation on how to develop and support relationships between individuals with disabilities and typical people. The article begins by describing common experiences of people with disabilities, experiences of exclusion, devaluation, and being forced into a "client" role, and shows how these limit opportunities to participate in a netowrk of family, friends and acquaintances. The author then discusses factors that may be involved in developing and maintaining relationships, including opportunity, support, diversity, continuity, intimacy, and freely given and chosen relationships. She focuses on two themes that arise from writings about relationshuips between people with disabilities and typical people: Their perceptions of their relationships as ordinary, not unusual; and their

descriptions of the commonality and reciprocity between the friends in the relationship. Finally, she discusses the dilemmas facing human service workers hoping to promote friendships for the people they support.

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TITLE: Regenerating community

AUTHOR: McKnight, J. L.

PUBLICATION INFORMATION: 1987

Social Policy, Winter, 54-58.

McKnight begins this article with a discussion about problems with two primary orientations of social policy: institutions and individuals. He argues that the institutionalized social service system does not effectively meet the needs of individuals. Rather, it is a "design established to create control of people." As an alternative, he proposes that we look at the community--a structure of associations based on consent--to meet the needs of people. The "community of associations" is characterized by features such as interdependence, creativity, citizenship, and including: capacity, collective effort, informality, stories, celebration, and tragedy. McKnight argues that institutionalized systems grow at the expense of communities, and that instead of continuing to strengthen service systems we should work to strengthen communities. He concludes, "There is a mistaken notion that our society has a problem in terms of effective huamn services. Our essential problem is weak communities."

This short article will be of interest to people in the human services field--particularly those who are frustrated or dissatisfied with the social service system and its ability to meet people's needs. The challenge presented to human service workers, based on this article, is to see their role as one of helping people establish community connections and associations rather than more social service ones.

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TITLE: What are we learning about bridge-building?

AUTHOR: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
73 Indian Drive
Manchester, CT 06040

This monograph opens with the key premise of "bridge-building." "Real integration, the development of genuine networks of support, requires very focused

and assertive effort(s) on behalf of facilitators who initiate, support and maintain new relationships. We call these facilitators bridge-builders because they build bridges and guide people into new relationships, new places, and new opportunities in life" (p. 1).

As the sub-title of the monograph suggests, it is a summary of a dialogue between people who are trying to build community for and with people with disabilities by working as bridge-builders. Most of the monograph presents the reflections of five participants at a day-long discussion on bridge-building in 1988. As this publication appears to be a faithful rendering of people's words, with little attempt at a full written explication of the concepts and terms that form the new language of bridge-building, it may be unsatisfying for someone who is completely new to the idea. However, it does contrast the different perspectives held by proponents of traditional human services with that of bridge-building, and would be of interest to those readers already acquainted with this concept.

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TITLE: What are we learning about circles of support?

AUTHOR: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
73 Indian Drive
Manchester, CT 06040

The authors offer the experiences of several "circles of support" now in existence in Connecticut. Inspired by the efforts of the Joshua Committee over the past decade, the authors helped found cirlces of support around several people with disabilities. "A circle of support is a group of people who agree to meet on a regular basis to help the person with a disability accomplish certain personal visions or goals" (p. 3). The monograph gives practical information on the process of starting and maintaining a support circle, with several actual examples. Circles of support serves well as both an introduction to the concept and as a useful resource for people already familiar with the issue.

Acknowledging the current fascination with "personal futures planning," the authors provide an important comparison of support circles with person-centered and traditional methods of service planning. And they wisely caution that the process outlined in the monograph is not meant as a model for replication of other support circles. Rather, "the spirit of a circle...is more important than the details of the process, and we hope that the process we describe will help people invite the spirit of support into the lives of other people" (p. 1).

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TITLE: The gift of hospitality: Opening the doors of community life to people with disabilities

AUTHOR: O'Connell, M.

PUBLICATION INFORMATION: 1988

The Community Life Project
Center for Urban Affairs and Policy Research
Northwestern University
2040 Sheridan Road
Evanston, IL 60208
(312) 491-3395

This monograph is part of the growing literature which critiques the human service system even when it is based in the community. It describes the efforts of people with a variety of disabilities to take their place within the community and by others to accept them. O'Connell asserts that community-based services can isolate people with disabilities from community life. Surrounded by paid staff, many clients in the human service system are cut off from the opportunities to meet and develop relationships with typical people.

By sharing the experiences of individuals with disabilities who have been welcomed into the hearts and lives of others, O'Connell introduces a practical definition of hospitality. She suggests that hospitality is "...the fundamental sense that you have to appeal to in asking other people to get involved in this work of welcoming isolated people back into the community." For the author, achieving the fullest possible integration of individuals with disabilities into society involves acts of welcome and hospitality by those who are already members.

This monograph would be useful reading for those interested in the meanings of "community integration" for people with disabilities.

TITLE: Circles of friends

AUTHOR: Perske, R./Illustrated by Perske, M.

PUBLICATION INFORMATION: 1988

Abingdon Press
201 Eighth Avenue, South
P.O. Box 801
Nashville, TN 37202

Circles of friends presents several stories of friendship between people with disabilities and those who are not disabled. After conducting interviews across Canada and the United States, the Perskes provide readers with several vignettes of friendships. They refer to these relationships as "living documents," proof that people "...once thought too limited or strange for life in ordinary neighborhood" enjoy a variety of friendships. The story and illustrations are alternately powerful, humorous, touching and life-affirming. This book is an upbeat account of the possibilities of friendship and is meant for a wide audience, both within and outside the field of mental retardation.

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TITLE: New life in the neighborhood: How persons with retardation and other disabilities can help make a good community better

AUTHOR: Perske, R./Illustrated by Perske, M.

PUBLICATION INFORMATION: 1980

Abingdon Press
201 Eighth Avenue, South
P.O. Box 801
Nashville, TN 37202

Written by well-known author and leader in the field of developmental disabilities, Robert Perske, New life in the neighborhood presents a compelling case for the integration of people with developmetnal disabilities into typical neighborhoods and communities. The book provides a clear and straightforward explanation of normalization, debunks the myths surrounding people with mental retardation, explains why both tyipcal and disabled people benefit from community integration, and addresses commonplace fears such as the impact of small community residences on property values. Sensitively and clearly written, this book is directed toward a popular audience, including civic leaders, prospective neighbors of the community residences, volunteers, and other non-professionals. This is a key source for anyone involved in developing integrated community living arrangements.

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TITLE: Social integration and friendship

AUTHOR: Strully, J. L., & Bartholomew-Lorimar, K.

PUBLICATION INFORMATION: 1988

In S. M. Pueschel (Ed.), The young person with Down Syndrome: Transition from adolescence to adulthood. Baltimore: Paul H. Brookes.

In the first part of this chapter, Strully and Bartholomew-Lorimar neatly summarize the experiences of many people with disabilities at the hands of the human service system. By receiving services, individuals are turned into clients and become viewed primarily in terms of their particular disability. They are surrounded by programs and staff, and are cut off from typical people, places and events. One result of this is that people in the community come to believe that segregation is an appropriate response to people with disabilities.

The authors propose that freely-given friendships between typical and disabled people "...are at the root of developing competent, caring communities for us all." They then present two case studies illustrating how to enable a person with disabilities to develop such friendships and the impact of these relationships for the people involved.

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TITLE: Friendship and our children

AUTHOR: Strully, J., & Strully, C.

PUBLICATION INFORMATION: 1985, Winter

Journal of The Association for Persons with Severe Handicaps, 10(4), 224-227.

The Strullys describe the friendship between one of their daughters, Shawntell, and one of her schoolmates, Tanya. They conclude that it is primarily through enjoying a number of close relationships and/or friendships with typical people that their daughter will be guaranteed a place in her community.

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TITLE: On accepting relationships between people with mental retardation and non-disabled people: Towards an understanding of acceptance

AUTHORS: Taylor, S. J., & Bogdan, R.

PUBLICATION INFORMATION: 1989

Disability, Handicap & Society, 4(1), 21-36.

This article outlines the "sociology of acceptance" as a theoretical framework for understanding some relationships between people with mental retardation and typical people. As a point of departure, the authors review sociocultural perspectives on deviance and explore their contribution to the study of mental retardation. Based on qualitative research at community programs for people with severe disabilities, the authors next examine the nature of accepting relationships and describe four sentiments expressed by typical people which account for their relationships with

people with mental retardation: family; religious commitment; humanitarian sentiments; and feelings of friendship. The article concludes with a brief discussion of the implications of a sociology of acceptance for the field of mental retardation.

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TITLE: Ties and connections

AUTHOR: Tyne, A. (Ed.), et al.

PUBLICATION INFORMATION: 1988

King's Fund Centre
126 Albert Street
London, England NW1 7NF

This monograph is worth sending to England for. It attempts one of the more comprehensive discussions of interpersonal relationships in the lives of people with developmental disabilities (who are referred to in the publication as having "learning difficulties"). The monograph begins with descriptions of some of the types of relationships that pople have and/or desire more of. These include friendship, acquaintances, organizational membership, being part of a family and a neighborhood. Some basic, common-sense strategies that families, disabled individuals, service workers and "typical citizens" might undertake in order to help maintain and increase the existing relationships in a person's life are outlined. The third and last chapter is a cautionary one that explores some of the difficulties faced by people with handicaps in developing a wide range of personal relationships.

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TITLE: The new genocide of handicapped and afflicted people

AUTHOR: Wolfensberger, W.

PUBLICATION INFORMATION: 1987

Division of Special Education and Rehabilitation
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2180
(Copyright of W. Wolfensberger)

In this monograph, Wolfensberger attempts to describe the dangerous and life-threatening position that people with disabilities are currently placed in, largely because of their devalued status. The first sections of the monograph describe the "...negative experiences that befall devalued people," and would be appropriate reading for people interested in the process of turning people into clients.

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TITLE: Citizen Advocacy and protective services for the impaired and handicapped

AUTHOR: Wolfensberger, W., & Zauha, H. (Eds.)

PUBLICATION INFORMATION: 1973

Toronto: National Institute on Mental Retardation.

TITLE: CAPE: Standards for Citizen Advocacy program evaluation

AUTHOR: O'Brien, J., & Wolfensberger, W.

PUBLICATION INFORMATION: 1980

Toronto: The Canadian Association for the Mentally Retarded.

TITLE: Learning from Citizen Advocacy programs

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1987

Atlanta: Georgia Advocacy Office.

As a concept put into practice, Citizen Advocacy (C.A.) is twenty-two years old. Formulated by Dr. Wolf Wolfensberger, it was part of a larger schema that delineated advocacy and protective services needed by people with mental retaration. These services were designed to provide the necessary protection for handicapped individuals who were unable to represent themselves and had no family or friends to safeguard their interests. Citizen Advocacy was an attempt to respond to the parents' question, "What will happen to my disabled son or daughter when I'm gone?" Wolfensberger defined Citizen Advocacy as "...a mature, competent citizen volunteer representing, as if they were his own, the interests of another citizen who is impaired in his instrumental competency, or who has major expressive needs which are unmet and which are likely to remain unmet without special intervention" (Wolfensberger & Zauha, 1973).

CAPE (O'Brien & Wolfensberger, 1980) is an evaluation tool designed to compare the practices found in a Citizen Advocacy program to the standards set by the definition and principles of Citizen Advocacy. CAPE is made up of 36 ratings which examine the efforts of the staff and board to recruit and introduce people who require protection, practical assistance, and/or friendship (proteges, partners) to capable citizens who attempt to address those needs (advocates).

O'Brien's manual (1987) provides an expanded definition and rearticulates the principles of Citizen Advocacy This manual reflects the experiences of people in the United States, Canada, England, and Australia trying to put Wolfensberger's theory into practice. Learning from Citizen Advocacy programs is a collection of questions,

activities, and resources about Citizen Advocacy While external evaluation teams may use the manual (O'Brien suggests the possibility of doing so in conjunction with the CAPE tool), boards and staff of Citizen Advocacy offices may also use it to review their own work.

Despite the different purposes of these publications, all of the authors assume that at least some typical citizens will choose to become involved in a personal, one-to-one relationship with someone who is devalued by the society at large. Those interested in the concept of Citizen Advocacy are encouraged to read all three of these publications.

WOMEN AND COMMUNITY CARE

Today when the disability field is working toward community integration of people with disabilities it becomes increasingly important to understand some of the broader social issues that are at work in society and influence community participation. One of these broader issues are gender relations. Society is fundamentally divided by gender lines and it is not unreasonable to assume that this influences the disability field as well as other aspects of society. Concepts like "community care," "informal care," "family care," and "informal supports" have become increasingly popular within the disability field. Caring is usually defined as women's responsibility, and women are often seen as the "natural" caregivers of people with disabilities and other dependent groups. But the fact that the responsibility for caring is still ascribed on the basis of gender has not gained much attention, and women's informal caring work has rarely been the center of focus within the disability field.

This section contains a selected review of the literature on women and community care. This literature is largely British and Scandinavian feminist scholarship that has criticized the policy of community care for assuming and depending on the substantial and consistent input of women's unpaid labor in the home. The literature argues that community care policies are based on an outdated understanding of women's roles in modern societies and suggests that if we do not develop new alternatives that are equally sensitive to women's issues as to disability issues, we may face serious dilemmas that could turn out to be damaging for current attempts to pursue community integration of people with disabilities.

TITLE: Ideologies of caring: Rethinking community and collectivism

AUTHOR: Dalley, G.

PUBLICATION INFORMATION: 1988

Macmillan Education
Houndmills, Basingtoke
Hampshire RG21 2XS
ENGLAND

This book reflects the author's attempt to answer questions about the relationship between feminism, notions of collectivism, and present-day community care policies. She sets out by examining the development of community care policies and what they mean for women and for dependent people. Thereafter follows an analysis of familism which the author links with the wider ideology of possessive individualism. Dalley argues that current thinking about care is based on the principles of familism and possessive individualism and that these could and should be replaced with the principle of collectivism. Society as a whole should take responsibility for its weakest members and the principle of collective responsibility could lead to different and more effective forms of care which are acceptable to the people who need care and allows them to maintain their dignity. The book presents an important step forward in the discussion and understanding of community care. It builds upon previous work, especially the groundwork done by feminist writers who have provided the critique of contemporary approaches to informal care. An interesting and thought-provoking book.

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TITLE: Community care: Developing non-sexist alternatives

AUTHOR: Finch, J.

PUBLICATION INFORMATION: 1984

<u>Critical Social Policy</u>, <u>9</u>, Spring 1984, 6-18

This article is a part of an ongoing debate in Britain, a debate "...prompted by feminist analyses of community care, by considering whether any form of community care for dependent adults can be non-sexist" (page 6). This debate is based on British culture and traditions as well as current British policies and practices. Therefore, the context and some of the concepts are different from concepts used in the North American literature. What is most strikingly different in the British debate about "community care" and the U.S. debate about "community integration" is that the British focus is broader; it is based within a political ideology, discusses the possibilities of reform within current political realities versus the necessary larger scale political reform. It integrates feminist perspectives, discusses the family, the "community" and "care" critically as it appears in daily lives of people and within a broader social policy perspective.

The article is written from a feminist perspective but the author is also actively sympathetic to disability issues and emphasizes the need to develop versions of community care in ways we find acceptable for the people cared for. The article provides a critical analysis of some of the new British attempts to develop locally based services which entail a close partnership between formal and informal sources of care which also include more autonomy of direct care staff and control by the

users of services. After an examination of these alternatives Finch concludes that the "caring" envisaged in these new community care alternatives will remain women's work for the foreseeable future, both for economical and ideological reasons. Finch further argues that the "community" is not just a women's space but it must necessarily be so. This leads her to a pessimistic conclusion about the possibilities of non-sexist community care alternatives in the near future. She suggests that there seems to be little hope for change without social and cultural transformation of a very fundamental nature.

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TITLE: A labour of love: Women, work and caring

AUTHOR: Finch, J., & Groves, D. (Eds.)

PUBLICATION INFORMATION 1983

Routledge & Kegan Paul
9 Park Street
Boston, MA 02108

This volume consists of 8 chapters which examine various issues in the lives of women who provide unpaid care for children and adults who have handicaps, are chronically ill, or elderly. The chapters are organized in 3 sections: (1) The Social Context of Caring; (2) The Experience of Caring; and (3) The Economics of Caring. The central focus of the book is on the tension between women's economic independence (actual, potential or desired) and their traditional role as unpaid caregivers. The ten contributors to this volume explore different facets of women's experience of caring, the dilemmas which caring poses for women and the social policy issues raised by the particular topics under discussion. This book was one of the first attempts to give a comprehensive analysis of women's informal caring work. It still remains one of the most important and much cited books on this issue.

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TITLE: Women and family care: On the gendered nature of caring

AUTHOR: Traustadottir, R.

PUBLICATION INFORMATION: 1988

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $1.70 plus 10% shipping and handling

This paper is based on a qualitative study of families of children with disabilities and the services that provide support to these families. The study challenges the traditional view of families and attempts to explore how stereotypical sex roles influence the caring for a child with a disability within the family. It also examines how traditional ideas and values about the roles of men and women influence the way family support services are provided. The paper provides an analysis of the meaning of care as work (caring for), love (caring about), and as the extended caring role (caring about what happens to people with disabilities in general). The author concludes that the disability field needs to develop a more sensitive perspective on women's issues to further efforts to achieve full community integration of people with disabilities.

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TITLE: Policy is personal: Sex, gender and informal care

AUTHOR: Ungerson, C.

PUBLICATION INFORMATION: 1987

Travistock Publications
(in association with Methuen)
29 West 35th Street
New York, NY 10001

This British book is based on in-depth interviews with nineteen people who provide care for frail and elderly family members. Fifteen of these caregivers are women and four are men. The author describes the lives and experiences of these "carers" (as she calls caregivers) in rich detail and manages to portray her informants in such a way that they come alive on the pages.

The Introduction places the book in the context of other British literature and research on caring and the British social policy of community care (which has many parallels to the U.S. social policy of community integration). The purpose of the book is to fill a gap in the literature on caring and explore, "...the way particular carers in a family constellation emerge, the way that carers talk about and construe the feelings they have about their work, the impact of caring on the relationship between carer and cared for" (page 2).

The findings of this study are fascinating and help develop our understanding of the complicated nature of family care. For example, in an attempt to explain why a particular individual within the family network becomes a carer, Ungerson demonstrates that not all kinship ties are equal. Instead, there is a hierarchy of kinship obligations and carers are "selected," first and foremost according to dominant normative and gendered rules of kinship. In this ranking of kinship obligations, close female kin, especially daughters, are believed to have greater obligation to provide care than sons, and daughters-in-law are expected to serve as primary caregivers when no daughters are available. Another of Ungerson's interesting findings is that there were significant differences between men and women carers, both in terms of who they cared for, the reasons they gave for providing care, and at what point in their lives they became carers.

Although this book deals with caregivers who are caring for elderly and frail family members, it provides valuable insights that further our understanding of the complicated nature of "family care" of people with disabilities.

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TITLE: A feminist perspective on the new ideology of "community care" for the elderly

AUTHOR: Waerness, K.

PUBLICATION INFORMATION: 1987

In Acta Sociologica, The Journal of the Scandinavian Sociological Association, (a Scandinavian journal published in English), 30(2), 133-150.

This article is written by a Norwegian woman, Kari Waerness, and focuses on "community care" of elderly people. It draws mostly upon the Norwegian situation but refers also to the care for elderly people in other Scandinavian countries. Although the article doesn't focus on people with disabilities, the author relates some of the arguments to people with disabilities. In addition, many of the principles involved are the same and much of the arguments are equally applicable to the community care/community integration of people with disabilities. The article is embedded within the Scandinavian culture and welfare system. Therefore, the context and the concepts used are somewhat different from what is found in the U.S. literature. The author starts out by claiming that the concept "community care" has a variety of meanings attached to it and can therefore be used as an ideology behind many different kinds of changes in social policy. She argues that much of the thinking about the desirability of community care is based on myths rather than realities and on an outdated understanding of women's roles in family and society. She points to the need for a future oriented social policy that is better fitted to combine the policy of community care and the goal of furthering greater equality between the sexes. The alternatives Waerness envisages include more flexible, comprehensive public care services to better coordinate informal and public care.

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TITLE: The meaning and social division of community care

AUTHOR: Walker, A.

PUBLICATION INFORMATION: 1982

In A. Walker (Ed.), Community care: The family, the state and social policy (pp. 13-39). Oxford: Basil Blackwell & Martin Robertson.

This chapter sets out to lay the foundations for a critical assessment of the concept of community care. It examines the meaning of community care from the

position of different groups involved; politicians, planners, policy makers, and those in need of care and their families. It also examines the social division of care, particularly between the state and the family. The chapter traces the official development of community care policies in Britain and examines the meaning of community care to the family which provides most of the care. It also discusses some possible future directions for community care policies which attempt to avoid the worst aspects of the current policy, particularly the disproportionate burden it puts on women and families.

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TITLE: Women, the "community" and the "family"

AUTHOR: Wilson, E.

PUBLICATION INFORMATION: 1982

In A. Walker (Ed.), Community care: The family, the state and social policy (pp. 40-55). Oxford: Basil Blackwell & Martin Robertson.

This chapter is written from a feminist perspective and argues that the concept "community" is often used in such a way that it should rather be understood as "family." This is especially true when it is used in connection with the provision of social and welfare services. Moreover, in this same context, the word "family" really means "women." The author criticizes both the concept and ideology of community as it has developed over the past century and suggests that it is riddled with reactionary implications and, in particular, with a vision of the family which is incompatible with women's liberation. The community, the author argues, is based on an ideology that oppresses women by silently confining them to the private sphere without so much as even mentioning them. The author calls for a new family policy and suggests that the family as it currently exists must change if not only women, but also men and children are to break out of their present situation and harmful behavior patterns based on the current sexual division.

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WOMEN WITH DISABILITIES

To make it easier for the reader to find materials on topics of specific interest, this division of the bibliography has been divided into the following four sections:

1. *General Issues*
2. *Education, Employment, and Rehabilitation*
3. *Health, Motherhood, and Reproductive Rights*
4. *Sexuality and Sexual Abuse*

Anyone looking for materials about the lives and experiences of women with disabilities a few years back would have found little to read. Today there is a growing body of literature addressing different aspects of the lives of women and girls with disabilities. These writings do not fall into one field of study, instead, they come from a wide range of disciplines and are often interdisciplinary in nature. As a result these materials are scattered across many fields of study which makes it hard to gain an overview of what already exists and even harder to know where to look for materials. Because of how hard it is to find writings about women with disabilities one frequently hears statements like, "There is nothing written about women with disabilities." Although much remains to be learned about women and girls with disabilities, this selected bibliography shows that there already exists a substantial body of literature on the topic.

This section is not a comprehensive listing of the literature on women with disabilities. Instead we have selected writings that reflect the diversity found within this literature. We hope this section will serve as a useful starting point for people who are looking for materials on women with disabilities.

GENERAL ISSUES

The writings listed in this section address the lives of women with disabilities in general. Among these are edited volumes covering a range of issues, as well as articles and books describing the lives of women with disabilities and/or providing theoretical frameworks to understand their situation.

TITLE: Disabled women in America: A statistical report drawn from census data

AUTHOR: Bowe, F.

PUBLICATION INFORMATION: 1984

President's Committee on Employment of the Handicapped
Washington, DC 20210

This 26-page report is based on data collected from the 1981 Current Population Survey of the Bureau of the Census and summarizes findings concerning women with disabilities. Although the primary focus is on the employment status of women with disabilities of working age (16-64 years old) who do not live in institution, it also provides statistical accounts of various other aspects in the lives of this group of women such as education, marital status, and so on. The report compares women with disabilities to two groups of people in the same age range; men with disabilities and women without disabilities.

Some of the report's findings are that only 19.9% of women with disabilities have work. Men with disabilities are almost twice as likely to have work: 36% of them are employed. At the same time 59.1% of non-disabled women in the same age range are working. Women with disabilities who work full time only earn 56% of what men with disabilities who have full time jobs earn. The average woman with a disability is 51 years old, has a high school level of education, is unemployed, and her income from all sources was less than $3,500 in 1980. This statistical summary is not very thorough but shows clearly the grim economic realities of women with disabilities.

TITLE: Women and disabilities: A national forum

AUTHOR: Boyle, G., Rioux, M., Ticoll, M., & Felske, A. W.

PUBLICATION INFORMATION: 1988

Entourage, 3(4), 9-13

This article grew out of a three-day conference about women and disability, held in June 1988 in Ottawa, Canada, and describes the major issues covered during the conference. The conference discussed issues of oppression of women with mental retardation in areas such as education, employment, reproductive rights, violence against women, motherhood, participation in the women's movement, and inclusion in research and policy development. The authors criticize the exclusion of women with mental retardation from the women's movement and state that the struggle for rights in these areas is a struggle which should be shared by all women.

TITLE: With the power of each breath: A disabled women's anthology

AUTHORS: Browne, S. E., Connors, D., & Stern, N. (Eds.)

PUBLICATION INFORMATION: 1985

Cleis Press, A Women's Publishing Company
P.O. Box 8933
Pittsburgh, PA 15221

The quality of writing of this collection of essays, poetry, interviews, and first-person account is uneven and the editors' articulate and informative introductions sometimes outshine the collected pieces. All the women who contribute to the book have a disability. Most of the book consists of first person account of being a female and having a disability, but a few conceptual pieces are also included. The stated purpose of the book is to "bridge the gap that separates women with disabilities from one another and from the non-disabled world" (p. 10) and the book reflects these women's resistance against the silencing of women with disabilities.

The editors set out with a strong political commitment to produce an anthology representative of all women with disabilities. Although that proved to be impossible the book addresses a broad spectrum of disability issues and the contributors cross the lines of race, age, class, sexual orientation, geographical location and type of disabilities. The book also includes interviews with women who are labeled mentally retarded a group which often has been excluded in the literature on women with disabilities. This book is born out of a group of women with disabilities who also are feminists and reflects their experiences of discrimination because of their disabilities in addition to the traditional sexism. The majority of the pieces in this book are angry and speak out with bitterness of the isolation, despair and powerlessness women with disabilities face in their lives. Some of the pieces are both inspiring and very moving.

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TITLE: Women and disability: The double handicap

AUTHOR: Deegan, M. J., & Brooks. N. A. (Eds.)

PUBLICATION INFORMATION: 1985

Transaction Books
Rutgers University
New Brunswick, NJ 08903

This book is the first major collection of scholarly writing about women who have disabilities and contains 11 chapters dealing with various aspects of the lives of women with disabilities. The major factors that unify this collection are a central focus on the double minority status of women with disabilities, the lack of information available about their lives and experiences, and the need to change the conditions that perpetuate the structural inequality women with disabilities experience.

Two of the chapters, Chapter 2, by Fine and Asch, "Disabled Women: Sexism without the Pedestal," and Chapter 4, by Deegan, "Multiple Minority Groups: A Case Study of Physically Disabled Women," provide a conceptualization of women with disabilities that have had a significant impact on other people's thinking and writing about women with disabilities. In her chapter, Deegan points out the multiple discrimination against women with disabilities; as a woman and as a person with a disability. Deegan's discussion of the effects of the multiple minority status of women with disabilities is useful in examining structural discrimination in employment, education and other areas. Fine and Asch's conceptualization of disabled women as "roleless" has already gained much note in subsequent literature. The remaining sections focus on specific types of disabilities and their consequences for women or

specific problem areas, such as mothering and self-help. Other issues covered are the economic effects of a multiple minority status and the negative consequences of present policies on the lives of women with disabilities.

The book is a beginning step in unraveling the interaction between more than one minority status being held concomitantly by an individual and a group. While the quality of the articles is not uniform, they all provide insights into the problems and experiences of these women and add immeasurably to the conceptual and theoretical understanding of the lives of women with physical disabilities. One shortcoming of the book is that it only deals with women who have physical disabilities. Another is that rather than examining class and race issues, it is dominated by white middle class views and values.

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TITLE: Women with disabilities: Essays in psychology, culture and politics

AUTHOR: Fine, M., & Asch, A. (Eds.)

PUBLICATION INFORMATION: 1988

Temple University Press
Philadelphia, PA 19122

So far, this is the most comprehensive edited collection of scholarly writing about women with disabilities. Fine and Asch, the editors of this volume, have, for a number of years, been involved in examining what it means to be a women with a disability in today's society. Their early conceptualization of the problems facing women with disabilities has influenced and informed other people's thinking. Now these two women have collected the work of 22 writers and thinkers to explore the psychological, cultural and political dilemmas currently faced by approximately 18 or 19 million women with disabilities in America. The volume covers a wide range of issues, reviews the most recent thinking on this subject and raises provocative new areas for future exploration.

The 13 essays in the volume are loosely organized in three categories; "Bodies and Images," "Disabled Women in Relationships," and "Policy and Politics." In addition there is a lengthy introduction by Asch and Fine where they review past work (and neglect) on this subject and point toward future exploration. The editors also close the book with an "Epilogue: Research and Politics to Come." Like all collections of essays, the quality is uneven. At the same time this is an important document about the lives of girls and women with disabilities in American society today. It is also notable that the editors have made attempts to cover broader issues than previous collections on women with disabilities. First, this volume covers a broader range of disabilities than many previous writings. An example of this the inclusion of women with developmental disabilities, a group that has traditionally been neglected in volumes on women with disabilities. Second, the volume deals with issues that often have been neglected such as disability and ethnicity; the moral dilemma between a reproductive rights and disability rights; and an analysis of the

exclusion of women with disabilities from the women's movement. The volume also includes a discussion about girls with disabilities. This is a book that everyone interested in the lives and experiences of women with disabilities should read.

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TITLE: Voices from the shadow: Women with disabilities speak out

AUTHOR: Matthews, G. F.

PUBLICATION INFORMATION: 1983

The Women's Educational Press
16 Baldwin Street
Toronto, Ontario, Canada

This book explores the lives of women with disabilities in Canada and is based on interviews with 45 women with disabilities. The author herself has a physical disability and the book is a mixture of her own autobiography and the interviews. The result is a very readable and interesting account of the lives of women with disabilities, some of whom live in institutions and others who live in the community.

The book is candid in its critique of the medical and rehabilitation professionals, institutions and the attitudinal and physical barriers in society. It explores the feelings of women with disabilities about themselves and their relationships with others. It points out that many doctors and social workers as well as society in general think that women with disabilities are asexual and therefore not in need of information on birth control or what is possible in the way of having children or a sex life. Other issues addressed are employment, education, housing, parenting, accessibility and social and governmental assistance.

The introduction to the book is written by Pat Israel and Cathy McPherson, "two feminists with disabilities" (as they call themselves). They discuss, amongst other things, the relations between the disability rights movement and the women's movement and criticize how un-accessible the women's movement has been for women with disabilities.

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TITLE: Bridging the gap: A national directory of services for women and girls with disabilities

AUTHOR: National Clearinghouse on Women and Girls with Disabilities

PUBLICATION INFORMATION: 1990

Educational Equity Concepts
114 East 32nd Street
New York, NY: 10016

The National Clearinghouse on Women and Girls with Disabilities has compiled a national directory of services and support groups for women and girls with disabilities. This document contains more than three hundred listings of organizations that provide services to meet the needs of women and/or girls with disabilities. Each entry includes organization name, address, telephone number, contact person, region served, date established, whether they respond to inquiries by phone or by mail, if they have a newsletter, and a brief description of their programs and services. The services included in this directory cover a wide range of areas of importance for women with disabilities such as educational services and offices of disability services at universities; support groups and other self-help groups for women with disabilities; government and non-government organizations focusing on or including women with disabilities; generic services which also provide services for women with disabilities such as rape crises and planned parenthood; and more. This is a unique directory that will be of extreme importance for women with disabilities in terms of breaking the isolation they so often experience and helping them find appropriate services and supports. As the first national directory of services and support groups for women with disabilities, it will undoubtedly serve to help women with disabilities find each other and build connections.

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TITLE: Disabled, female and proud! Ten stories of women with disabilities

AUTHOR: Rousso, H. (Ed.)

PUBLICATION INFORMATION: 1988

Exceptional Parent Press
605 Commonwealth Avenue
Boston, MA 02215

This book is edited by Harilyn Rousso, a woman with a disability, with photographs by Flo Fox, a visually-impaired photographer, and written by ten contemporary women with disabilities. These ten women offer their experiences and ideas about work, relationships, pregnancy, motherhood, life-styles, and how they got to where they are now. Each woman discusses the prejudice, barriers and difficulties she faced and offers advice to the reader about how to overcome these. The jobs these women hold span a variety of fields, some of them work in the creative arts; others in mathematics and science; some work in business; and others in human services. The ten women have various disabilities, and are of diverse age, race, class and language backgrounds.

The book grew out of the work of Harilyn Rousso, a social worker and therapist, who created a big-sister project for women and girls with disabilities in New York City to address the lack of role models in the media and the community, for young women with disabilities. The book is intended to serve as a much needed resource to counteract the isolation so many women with disabilities experience in their struggles with work and life. It is also intended to provide positive role models for women and girls with disabilities.

TITLE: With wings: An anthology of literature by and about women with disabilities

AUTHOR: Saxton, M., & Howe, F. (Eds.)

PUBLICATION INFORMATION: 1987

The Feminist Press
New York

This is a collection of literary writings by and about women with disabilities. This anthology of essays stories, and poetry conveys the experiences and feelings of women with disabilities. Among the 30 contributors to this book are such well-known names as Alice Walker, Adrienne Rich, Muriel Rukeyser, Vassar Miller, Nancy Mairs, Laurel Lee and Mary Wilkins Freeman. A powerful and moving book about the strengths, the struggle, the dignity, the intelligence, the humanity, and the courage of women with disabilities.

TITLE: Women with disabilities: Issues, resources, connections

AUTHOR: Traustadottir, R.

PUBLICATION INFORMATION: 1990

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $5.70 plus 10% shipping and handling

The materials that have been compiled into this information package on women with disabilities are intended to serve as an introduction for those who are interested in learning about the lives of women and girls with disabilities and the specific issues they face in today's society. In addition to introducing the lives and experiences of women with disabilities, the primary purpose of this package is to provide an overview of the existing materials in an attempt to make them more accessible to those who are interested in this topic.

The package is divided into four parts. PART I contains an article which provides an overview of the literature and some of the major issues facing women with disabilities in today's society. PART II is an annotated listing of resources written by and/or about women and girls with disabilities. PART III contains information about teaching materials about women and girls with disabilities. This part also lists other practical materials, such as a manual for accessibility. PART IV provides information about where to find services and support groups for women and

girls with disabilities and how to start networking projects. This part also contains information about women's periodicals and organizations which include women with disabilities.

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TITLE: Building community: A manual exploring issues of women and disability

AUTHOR: Women and Disability Awareness Project

PUBLICATION INFORMATION: 1989

Educational Equity Concepts
114 East 32nd Street
New York, NY 10016

This manual examines the connection between discrimination based on gender and discrimination based on disability, and addresses disability as a political issue; civil rights issue; as a human relations issue; and as a personal experience. It is intended to build community between diverse groups. The authors point out that the lack of opportunities within schools and organizations to learn about what it means to be a person with a disability results in widespread ignorance about people with disabilities. The authors intend the manual partly for use in schools as a general introduction to the topic, for teachers as well as students, and partly used within women's organizations to raise general awareness about issues faced by women with disabilities and strategies to meet the needs of women with disabilities within the organizations. In disability rights organizations the manual could serve to raise awareness about the particular needs of women with disabilities and how their lives and experiences differ from those of men with disabilities. In both women's and disability organizations the manual can be used to train staff as well as to inform the general membership about the connection between discrimination based on gender and disability.

The manual contains background information on disability rights issues and about women and girls with disabilities, an annotated bibliography and selected readings about women with disabilities. Lastly, the manual contains very practical guidelines and materials to conduct workshops on women with disabilities, including workshop formats that will allow activists, educators, and other trainers to explore disability issues in a wide variety of settings. This is a very practical and informing manual for anyone interested in the connection between gender and disability.

This manual was first published in 1984. The 1989 edition has been expanded to include the specific needs of young women with disabilities.

EDUCATION, EMPLOYMENT, AND REHABILITATION

While all students, males and females, with and without disabilities are subject to sex-biased assumptions in most schools and curriculum, research seems to indicate that sex-role stereotyping may be even more pervasive when students have disabilities. This seems to hold true for all levels of education. This section also lists writings that explore the discrimination against women with disabilities within rehabilitation and other special services, as well as in the labor marked in general.

TITLE: The disabled women's education project: Report of survey results

AUTHOR: Disability Rights Education and Defense Fund

PUBLICATION INFORMATION: 1983

Disability Rights, Education, and Defense Fund
1616 P Street, N.W., Suite 100
Washington, DC 20036

This reports the results of a survey of 8,000 people with disabilities around educational issues. The survey found, among other things, that girls with physical disabilities were more likely than boys with physical disabilities to be placed in segregated special schools. The authors suggest that these differences steam from the assumption that males must support themselves and therefore need a better education. The survey also suggests that women with disabilities tend to receive counseling that channels them into a lower paying jobs rather than more highly paid, high status professions.

TITLE: Lessons from life: Personal and parental perspectives on school, childhood, and disability

AUTHOR: Ferguson, P. M., & Asch, A.

PUBLICATION INFORMATION: 1989

In D. Biklen, D. Ferguson, & A. Ford (Eds.), Schooling and disability, (pp. 108-140).

University of Chicago Press
5801 Ellis Avenue
Chicago, IL 60637

This chapter draws upon personal narratives of people with disabilities and their parents as well as the authors' personal experiences. One of the authors, Adrienne Asch, is blind; the other, Philip M. Ferguson, is a father of a young man with a disability. Weaving together peoples' personal accounts of having a disability and their own experiences the authors discuss various issues that have to do with schooling and disability. Those who are interested in learning about how girls with disabilities experience schools should find Adrienne Asch's descriptions of her school years an interesting reading.

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TITLE: The influence of sexism on education of handicapped children

AUTHOR: Gillespie, P., & Fink, A.

PUBLICATION INFORMATION: 1974

Exceptional Children, 41(3).

The authors of this article suggest that sex-role stereotyping is especially pervasive for children who have mental disabilities and behavioral problems. These children tend to be taught traditional sex-role modes of behavior because that will supposedly enable them to better adjust to society. The authors also claim that schoolbooks for children with disabilities tend to include stories and illustrations that are deliberately sex-role stereotypical in order to foster this adjustment.

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TITLE: Demographic analysis related to successful job retention for competitively employed persons who are mentally retarded

AUTHOR: Hill, J. W., Hill, M., Wehman, P., Banks, P. D., Pendleton, P., & Britt, C.

PUBLICATION INFORMATION: 1985

In P. Wehman & J. W. Hill (Eds.), Competitive employment for persons with mental retardation: from research to practice (Vol. I).

Rehabilitation Research and Training Center
School of Education
Virginia Commonwealth University
Richmond, VA 23284-0001

This is a long term study of 155 people with mental retardation age 16-66, who were been placed in various competitive jobs by one supported employment program. This study focuses on the demographic characteristics of these people and their families and relates those to a successful vocational outcome defined as "retention in employment six months after the date of first placement (page 69). Among the

findings were that the majority of people being placed through the program were males, or 66%, while females represented only 34% of those who received jobs through the program. The study also reports that males were more likely to reach the successful retention rate of 6 months, or 70%, compared to 55% of the females. The authors discuss possible reasons for this gender inequality. Although this study does not focus solely on the disadvantage employment status of women with mental retardation it is a significant contribution because it is perhaps the only study that has examined gender differences in employment of people with mental retardation.

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TITLE: Benefits for the disabled: How beneficial for women?

AUTHOR: Kutza, E. A.

PUBLICATION INFORMATION: 1985

In M. J. Deegan, & N. A. Brooks (Eds.), Women and disability: The double handicap (pp. 68-86).

Transaction Books
Rutgers University
New Brunswick, NJ 08903

This chapter examines the impact of current U.S. disability policy on women with disabilities. The author examines some of the major programs designed to assist people with disabilities, such as disability insurance, supplemental security income, workers' compensation and vocational rehabilitation. She argues that because of the relationship of these programs to labor market participation, these program disadvantage women. Not only do women receive fewer benefits than men, they also receive lower benefits. The author concludes that there is an urgent need for reassessment of the impact of current disability policy on women with disabilities because current disability programs do not protect women with disabilities from economic threats associated with disability.

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TITLE: Region V study of access, services and benefits from vocational rehabilitation 1972 to 1984: A gender perspective

AUTHOR: Region V Research Study Group

PUBLICATION INFORMATION: 1987

Research and Training Center
Stout Vocational Rehabilitation Institute
School of Education and Human Services
University of Wisconsin-Stout
Menomonie, WI 54751

This is a report from a three year research project. The focus of the study was equity in the delivery of rehabilitation services to men and women. The purpose was to determine whether there were systematic gender differences along input, program, and output dimensions in the state vocational rehabilitation programs in Region V over a 13 year period; 1972-1984. Data for the study were drawn from data files that are submitted annually by each state agency to the Rehabilitation Services Administration. The results indicate a serious problem of inequity in the impacts of the vocational rehabilitation program on men and women with disabilities. The research clearly demonstrated that women did not acquire financial resources and occupational success at the conclusion of rehabilitation comparable to those achieved by men.

The report raises very direct issues regarding the current situation and makes some suggestions about change in policy, procedure, and practices in rehabilitation programs that can change the inequalities in access, services and outcomes for men and women with disabilities. This report should be of interest to people working within rehabilitation services as well as the people who use these services. Those interested in combining gender and disability issues would also find this an interesting study. The main problem with the report is that it uses technical language and is not very readable.

The January/February/March 1989 issue of the Journal of Rehabilitation has an article which also reports on findings of this study. The article covers similar issues as the report. The authors are Menz, Hansen, Smith, Brown, Ford, & McCrowey and the title is "Gender equity in access, services and benefits from vocational rehabilitation."

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TITLE: Women and work: Implications for mental health

AUTHOR: Sales, E., & Frieze, I. H.

PUBLICATION INFORMATION: 1984

In L. E. Walker (Ed.), Women and mental health policy (pp. 229-246).

SAGE Publications
P.O. Box 5084
Newbury Park, CA 91359

One of the most noted social trends in recent decades is the dramatic increase in women's labor force participation. This chapter examines what implications this may have for women's mental health. Because women have been heavy users of mental health services some authors have suggested that women's increased labor force participation, especially mothers with young children, might increase stress and result in more mental health problems. Others have suggested that because work is central to adult adjustment and a major source of satisfaction, women's increased labor force participation should have the opposite effect; it should improve their mental health. After a thorough review of the literature on the topic the authors conclude that the evidence regarding the mental health consequences of work for

women shows many positive relationships and few negative effects have been found. They state that work is clearly an source of self-esteem and satisfaction for most women. They also point out that the group of women who are most at risk of having mental health problems are non-white, nonmarried, nonemployed women, and women who lived in social isolation with limited roles. This suggests that the women who may most need mental health services may be those not in the work arena, especially women who are isolated or homebound because of young children or limited social roles.

HEALTH, MOTHERHOOD, AND REPRODUCTIVE RIGHTS

The specific health needs of women with disabilities seem to have been ignored for the most part by writers in disability field, as well as by the women's health movement. Listed below are two recent women's health books which have included women with disabilities and two pieces that address health issues for this group of women. The resources in this area seem to be scarce and hard to find. Resources addressing the health needs of women with disabilities in general, and pregnant women with disabilities in particular, have been scarce. This section also lists writings on reproductive rights presenting different viewpoints and arguments around the moral dilemmas between disability rights and women's rights.

TITLE: Real moral dilemmas

AUTHOR: Asch, A.

PUBLICATION INFORMATION: 1986

Christianity and Crisis, 46(10), 237-240.

This issue of Christianity and Crisis is a special issue on abortion. In her article, Adrienne Asch reviews the feminist case for women's right to reproductive choice and concludes that she supports the feminist case for legal abortion. But she seriously questions the wisdom of selective abortions of fetuses of the "wrong sex" or fetuses that have been diagnosed as having a disability, such as Down Syndrome or spina bifida. Asch's argument against selected abortions is based on the her view that support for women's equality with men should not be obtained by subverting other people's equality or potentiality, i.e., people with disabilities or people of a certain sex. This is a very thoughtful article which devotes much of its attention to the moral dilemma between disability rights and women's rights.

TITLE: On the question of Baby Doe

AUTHOR: Asch, A.
Rothman, B. K.

PUBLICATION INFORMATION: 1986

Health/PAC Bulletin, 16(6), 6-13.

This issue of Health/PAC Bulletin features two articles with the same name: "On the question of Baby Doe," where two authors, Adrienne Asch and Barbara Katz Rothman, address the rights of newborns with disabilities to medical treatment. The articles grew out of a public forum on reproductive rights and disability rights, sponsored by Health/PAC. The forum was brought about by an interest in the Baby Doe cases which seem to challenge the very core of the feminist movement, that is, the right of women to control their reproductive functions and to guide the fate of their offsprings. Although Asch and Rothman are both dedicated feminists, they have a fundamental disagreement on the treatment issues and present their arguments in distinctly different terms. A very interesting reading for anyone who is interested in these issues.

TITLE: The new our bodies, ourselves: A book by and for women

AUTHOR: The Boston's Women's Health Book Collective

PUBLICATION INFORMATION: 1984

Simon & Schuster
Simon & Schuster Building
Rockefeller Center
1230 Avenue of the Americans
New York, NY 10020

When Our bodies, ourselves was first published in 1969 there was practically no information easily available about women's health issues. The first publication of this book encouraged many women to explore the health issues most important to them. This new edition of Our bodies, ourselves has been considerably expanded from previous editions of the book. One of the additions is the inclusion of women who have disabilities and a disability perspective is presented in most chapters. Our bodies, ourselves has finally become a book on women's health issues for all women. Hopefully this book will serves as a model as to how other generic books on women's health, education, sexual abuse, and so on, can include disability issues as an integral part of the topic. Although the authors should be praised for including women with

disabilities it should also be mentioned that some issues of importance to women with disabilities get much less attention than needed. Examples of this are the problems some disabilities can cause during pregnancy and childbirth.

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TITLE: Parameters of successful and unsuccessful interventions with parents who are mentally retarded

AUTHOR: Budd, K. S., & Greenspan, S.

PUBLICATION INFORMATION: 1985

Mental Retardation, 23(6), 269-273.

This article examines interventions with parents who have mental retardation. The authors conducted a review of published and unpublished documents to determine the scope and outcome of such interventions. In addition, they report briefly on a survey they conducted of therapists' experiences in providing training to caregivers with mental retardation. The survey was conducted with families where the mother had been identified as having mental retardation. The survey results indicate that parent training programs for parents who have mental retardation tend to be more elaborate, more directive, and longer than the typical programs for parents without disabilities. The survey also indicates that about half of the families made substantial improvement on referral problems, but in only one-third of the cases were the therapists optimistic about the family's ability to function adequately without extensive continued assistance. Another interesting finding was that when the therapists determined whether parents were adequate caregivers they focused on the parents' behavior, not their intelligence and cognitive limitation was rarely mentioned as a reason to question parental custody of children. The authors conclude with a call for more research on how to help parents with mental retardation to function effectively as parents.

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TITLE: Women with disabilities: Abortion and liberation

AUTHOR: Davis, A.

PUBLICATION INFORMATION: 1987

Disability, Handicap & Society, 2(3), 276-284

In this article Alison Davis argues that the women's movement, which ideally should provide the perfect vehicle for women with disabilities to fight for and protect their rights, has failed to take this group of women into account. The author further argues that by supporting abortion on the grounds of a disability, the women's movement has, in fact, denied women with disabilities an identity as equal human beings, worthy of respect and has called into question the fundamental societal rights

of people with disabilities. Davis, who has spina bifida, describes how she changed her mind about abortion, from supporting abortion to being against it. Instead of seeing reproductive rights and disability rights as compatible, she argues that these are incongruous. She also argues that abortion is far from being a right, instead abortion underlines women's oppression and is counter-productive to women in general, and to women with disabilities in particular. This article takes a different perspective than most other available writing on these issues and should therefore be of interest to those who would like to review different arguments around the issues of reproductive rights and disability rights.

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TITLE: Ourselves growing older

AUTHOR: Doress, P. B., & Siegal, D. L.

PUBLICATION INFORMATION: 1987

(In conjunction with the Midlife and Older Women's Book Project and The Boston's Women's Health Book Collective.)

Simon & Schuster
Simon & Schuster Building
Rockefeller Center
1230 Avenue of the Americans
New York, NY 10020

Like its predecessor, Our bodies ourselves, this book builds upon the tradition of self-help and focuses on prevention and changes to create healthier life-styles. It is aimed at promoting self-acceptance of older and middle aged women by themselves and stresses the empowerment of midlife and older women in confronting the challenges of growing older. This is an informative book which covers a wide range of topics, including a variety of physical and mental ailments common to middle age and older women. Included throughout the text are practical tips for dealing with specific physical and mental problems. A resource guide in the back of the book lists articles of interest, a guide to community services and support groups. A good resource book.

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TITLE: The question of disability: No easy answers for the women's movement

AUTHOR: Fine, M., & Asch, A.

PUBLICATION INFORMATION: 1982

The Reproductive Rights Newsletter, 4(3), 19-20.

The intent of this article is to provide a feminist vision of reproductive rights and disability rights, and grows out of the authors outrage at the extent to which the reproductive rights movement has exploited disability toward its own ends. The authors describe how the disability movement and the reproductive rights movement share a tradition of a commitment to women's control over their bodies and access to resources to live full, sexual and meaningful lives. The authors argue that because the struggles of these two movements are intertwined, one battle cannot be won without the other, and feminists must stop exploiting disability issues for the aims of reproductive rights.

- -

TITLE: The tentative pregnancy: Prenatal diagnoses and the future of motherhood

AUTHOR: Rothman, B. K.

PUBLICATION INFORMATION: 1986

Viking Penguin
40 West 23rd Street
New York, NY 10010

The new technology that makes prenatal screening and diagnosis possible is usually celebrated by the medical establishment as a triumph for modern medicine as means to prevent disability. This technology is also seen as a way to improve the lives of families and societies. This book deals with this new technology but goes beyond the technology itself and looks at how it affects the lives of women who use it. This is a study of 120 women who have used amniocentesis, the most used form of prenatal testing. All the women in this study who received "bad diagnoses" (that is the fetus was diagnosed as having some form of a disability) made the decision to have an abortion. Rothman describes with great sympathy the pressure on women to use the technology and to undergo abortion if the fetus is "defective." Rothman sees these women as victims of technology, sacrificing themselves to spare their children from suffering.

The subject of this book is at the center of one of the dilemmas faced by feminists with disabilities, that is, feminists with disabilities who have participated in the fight for women's rights to control their own bodies, who are now faced with the fact that this right is used to selectively abort "defective" fetuses.

- -

TITLE: Special sisters: Health issues for mentally retarded women

AUTHOR: Sank, C., & Lafleche, E.

PUBLICATION INFORMATION: 1981

Off Our Backs, 11(5), 26-27

This article identifies and examines some of the health issues for women with mental retardation as well as describing the medical abuses this group of women has suffered from. Women with mental retardation have been especially vulnerable to forced sterilization, institutional abuse, medical experimentation and sexual abuse. They have been denied basic reproduction rights and some of the myths about women with mental retardation, such as the myth that they have uncontrollable sexuality, are still very much alive today. The authors criticize the women's health movement for ignoring women with mental retardation; they have not been included in self-help groups, their issues have not been raised in women's health books, and feminist resource books have not listed services that meet their needs. This is a very good article that raises many important issues that are rarely discussed elsewhere.

- -

TITLE: Women with disabilities: A survey of health-related experiences

AUTHOR: Savage, A., & Georgeson, S.

PUBLICATION INFORMATION: 1989

The Disabled Persons Assembly (NZ), Inc.
P.O. Box 143, 629 Main Street
Palmerston North, New Zealand

This book from New Zealand documents health experiences of women with disabilities. It is based on interviews with 60 women from three disability categories: 34 of the women had physical disabilities, 12 had intellectual disabilities, and 12 had psychiatric disabilities. The authors conclude by summarizing some of the findings of the study, and state that the experiences of these women show some fundamental issues about health and the health services they receive. Among the things they list are (1) lack of information regarding women with disabilities about the nature of their disability, as well as the implications of these disabilities; (2) lack of information about services available for women with disabilities; (3) the unequal relationship between health professionals and women with disabilities; (4) women with disabilities are not listened to and are excluded from decision making about their own health: (5) lack of information about side effects of medications; (6) disability is negatively viewed by health professionals and the general public alike; (7) women with disabilities fear being integrated into a community that does not have the resources to support them; and (8) women with disabilities view the availability of both personal and community support as vital.

The last sections of the book provides recommendation for change based on the findings of the study.

- -

TITLE: When a parent is mentally retarded

AUTHOR: Whitman, B. Y., & Accardo, P. J. (Eds.)

PUBLICATION INFORMATION: 1990

Paul H. Brookes Publishing Company, Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

Despite the fact that we have mixed feelings about this book we decided to include it because it was the only book we could find on the issue. Our major problem with the book is that we see it (or at least parts of it) as being too negative towards parents with disabilities.

People with mental retardation who live in the community are marring and having children. This book is, at least partly, an attempt to answer the question: How can we solve the right of people who have mental retardation to have and raise children, and the rights of these children to have their basic needs met? The book addresses a wide range of issues. The first section is devoted to an epidemiological perspective and describes the editors study of parents who have mental retardation. They found, among other things, a serious lack of support services for these parents and that 25% of their children had been removed from their care. They also claim that these parents and their children are "hidden and at high risk." Another chapter in this first section takes a medical perspective and looks at genetics and mental retardation. The section on educational interventions describes the experiences of two programs which provide training for parents with mental retardation. The section on legality and ethics reviews the rights of adults with mental retardation to marry and have children, as well as the potential conflict of those rights with children's rights to adequate parenting.

This book contains a significant amount of useful information but it is a bit confusing that the contributors to this volume do not agree with each other on fundamental issues. Even the editors report that they disagree on issues such as sterilization of people with mental retardation and the rights of persons with mental retardation to marry.

The book is written from a service provider's point of view and presents the "problem" as it is seen by those who provide services to parents with mental retardation. The book does not give insights into the lives of the parents or present their point of view. We do not learn what they think is important or what kind of support they identify as being important.

SEXUALITY AND SEXUAL ABUSE

The sexuality of women with disabilities is an area that has received a considerable amount of attention. While much of the writing in this area reflects the struggle of women with disabilities to be seen as sexual beings, listed below are also writings about sex-education, sex-therapies, and the specific problems women with mental retardation have faced in terms of their sexuality.

Sexual abuse of women and children with disabilities in another area that has received an increasing amount of attention. Much of this literature is based on studies that show that women with disabilities are at a much greater risk of being sexually abused than other women. This is true in society in general, and within residential facilities in particular. The literature listed below reflects these studies, as well as writings that have attempted to explain the increased vulnerability of women and children with disability to sexual abuse, and suggestions about what preventive measures can be taken. At the end of this section is a list of further resources on sexuality and sexual abuse.

TITLE: Facing the challenges of sexual abuse in persons with disabilities

AUTHOR: Cole, S. S.

PUBLICATION INFORMATION: 1984

Sexuality and Disability, 7(3/4), 71-88.

This article addresses causes, myths, and prevention of sexual abuse of people with disabilities. The author represents the view that sexual abuse has more to do with oppressive use of power than it has to do with sex. This leads her to examine the links between power structures, oppression and abuse, as well as the links between various forms of oppression. She states that it is essential to identify and change societal beliefs and norms which permit sexual abuse and exploitation to continue. The power structures in our society provides males with more power than females, able-bodied persons with more power than people with disabilities, and so on. This makes the less powerful, such as women, children, and people with disabilities likely candidates for sexual abuse. The author also draws parallels between incest within the family and sexual abuse of people living in residential facilities. Among the parallels are: (1) the abuser is usually someone the victim is physically or emotionally dependent on; (2) the perpetrators are frequently respected members of their communities; and (3) the victim can have confusing and conflicting feelings of love and hate towards the perpetrator. Among preventive measures the author recommends increased public awareness of how common sexual abuse is, assisting parents and staff to feel comfortable about all aspects of sexuality, identifying societal norms that contribute to abuse, and training and education for parents, caregivers, professionals, and individuals with disabilities.

TITLE: Responding to the sexuality of people with mental handicap

AUTHOR: Coley, L., & Marler, R.

PUBLICATION INFORMATION: 1987

In G. Horobin (Ed.), Sex, gender and care work (pp. 66-81).

St. Martin's Press
175 Fifth Avenue
New York, NY 10010

This chapter states that the sexuality of people with mental handicap has been largely ignored and in the few instances where it has been considered, the response has been restrictive and over-protective. (The book is British and uses the word mental handicap for mental retardation). The authors trace some of the restrictive attitudes to the way human services are operated. For example, many group homes are run by Christian groups who insist that residents live up to what is see as "Christian principles of high morals and values."

The authors state clearly that people with mental retardation have the same rights and needs to enjoy their sexuality as anyone else, and should have the same right to marry or cohabit as anyone else.

TITLE: Who cares? A handbook on sex education and counselling services for disabled people

AUTHOR: Cornelius, D. A., Chipouras, S., Makas, E., & Daniels, S. M.

PUBLICATION INFORMATION: 1982

Baltimore: University Park Press.

Based on a survey of 97 individuals with disabilities, the authors examine the myths that are created when we have a combination of disability and sexuality, and how both individuals and agencies react to the sexuality of people with disabilities. The authors state that, when we evaluate the responses of people and organizations, it is important that we differentiate between attitudes toward sexuality in general, attitudes toward disability in general, and attitudes toward disability and sexuality. The survey shows a discrepancy between the expressed need for services and what is actually available. Rather than creating special disability oriented services, the authors recommend the use of generic community based services.

TITLE: Sexuality, schooling, and adolescent females: The missing discourse of desire

AUTHOR: Fine, M.

PUBLICATION INFORMATION: 1988

Harvard Educational Review, 58(1), 29-53.

This article examines diverse perspectives on adolescent sexuality as well as current sex-education practices. The article is based on a thorough review of the literature, as well as the author's research on sex-education in public schools, and is informed by a study of numerous current sex-education curricula. The author identifies the three prevalent discourses of female sexuality inside public schools as being, (1) sexuality as violence, (2) sexuality as victimization, and (3) sexuality as individual morality. As a result, young women are educated primarily as the potential victim of male sexuality, they are not seen as sexual agents, and young women continue to be taught to fear and defend in isolation from exploring desires. The naming of desire, pleasure, or sexual entitlement, particularly for females, barely exists in the formal agenda of public schooling on sexuality. As an alternative to the prevailing discourses of female sexuality, the author presents a case for the discourse of desire, which would acknowledge female sexual desire and pleasure. Although this article does not mention people with disabilities it is very informing for anyone interested in female sexuality and sex-education, and provides an excellent framework to think about female sexuality and sex-education for all women, including women with disabilities.

TITLE: Sexual assault of handicapped individuals

AUTHOR: Longo, R. E., & Gochenour, C.

PUBLICATION INFORMATION: 1981

Journal of Rehabilitation, 47, 24-27.

Based on their work with sex offenders the authors report that rape and child sexual assault are not related to sex but to issues of control and power. Abusers will look for and use vulnerability to create the opportunity to rape. This vulnerability is increased in people who are marginalized, dependent and in need for affection. The authors describe ways to support victims of sexual assault and emphasize that support is equally important for people with disabilities as it is for anyone else.

TITLE: Patterns of institutional sexual assault

AUTHOR: Musick, J. L.

PUBLICATION INFORMATION: 1984

Response to Violence in the Family and Sexual Assault, 7(3), 1-2 & 10-11.

This article describes a study which was designed to identify patterns of sexual abuse of patients in psychiatric settings and the institutional practices which contribute to the vulnerability of patients. The findings in this article were primarily derived from an analysis of 80 separate incidents of assaults reported by 26 former mental patients, and about 100 separate incidents reported by 39 facility staff. Among the disturbing findings of this study was that the assaults were most frequently perpetrated by male direct-care staff. That is, by the staff patients were most dependent on and with whom patients had the greatest amount of contact. Assaults by male patients against female patents tended to be violent rapes, while male staff assailants most often did not use direct force, instead many took advantage of opportunities when female patients were completely helpless, in restraints or heavily medicated. The author also provides a very insightful analysis of the institutional practices and structures which contribute to the vulnerability of inmates to sexual abuse.

TITLE: Violence and sexual assault plague many disabled women

AUTHOR: O'Toole, C. J.

PUBLICATION INFORMATION: 1990

New Directions for Women, January/February 1990, 17.

This article reports that resent research indicates that battering and sexual assault figures may be two or three times higher for women with disabilities than for other women. The article criticizes the general sexual assault and domestic violence programs for ignoring women with disabilities, and the disability community for not having been able to solve this problem. The author suggests ways generic sexual assault and domestic violence services can use to reach women with disabilities and describes a few successful attempts to include this group of women in generic programs.

TITLE: Vulnerable: Sexual abuse and people with an intellectual handicap

AUTHOR: Senn, C. Y.

PUBLICATION INFORMATION: 1988

The G. Allan Roeher Institute
Kinsmen Building, York University Campus
4700 Keele Street
Downsview, Ontario M3J 1P3
CANADA

The author of this book claims that while sexual abuse has become a major issue in recent years, the sexual abuse of people with an intellectual handicap (i.e., mental retardation) has been virtually ignored in the public discussion and policy-making around the issue.

The author explores the myths surrounding sexual abuse and the myths surrounding people with mental retardation. The book focuses both on children and adults and the author shows how the myths surrounding disability contribute to the vulnerability of people with disabilities. This vulnerability seems to be well recognized, yet the author reports that it is almost impossible to get accurate measures of either prevalence or incidence of sexual abuse. Through a review of the literature which contributes to the understanding of sexual abuse of individuals with mental retardation the author suggests: (1) when sexual abuse is reported, 99% of the victims are assaulted by people known to them, (2) only 20% of assaults are reported, and (3) depending on the sampling and information gathering techniques used, estimates range from 25% to 83% of women, and up to 32% of men, with mental retardation have experienced sexual abuse. The author concludes that children with disabilities are at higher risk for sexual abuse than other children and adolescents, and that girls and women with disabilities are the most likely victims.

The author describes ways people with mental retardation use to indicate that they have been sexually abused and explores treatment and prevention issues. The book also addresses issues such as inaccessibility of services for individuals with mental retardation, offenders who have mental retardation, and legal issues in sexual abuse of children. The book concludes with recommendations to protect individuals with mental retardation from sexual abuse.

This book is, to the best of my knowledge, the first comprehensive study of sexual abuse of people with mental retardation.

TITLE: Sexuality, disability and abuse: An annotated bibliography

AUTHOR: Sobsey, D., Gray, S., Wells, D., Pyper, D., & Reimer-Heck, B.

PUBLICATION INFORMATION: 1990

University of Alberta
Severe Disabilities Program
6-102 Education North
Edmonton, AB T6G 2G5
CANADA

This annotated bibliography lists literature from a wide range of disciplines and perspectives relevant to sexual assault and abuse of people with disabilities. It is an attempt to provide a comprehensive review of the literature in this area and lists research studies, position papers, program descriptions, clinical reports, and media accounts. This should be an excellent resource for anyone interested in sexual assault and abuse of people with disabilities.

- -

TITLE: Talking about the best kept secret: Sexual abuse and children with disabilities

AUTHOR: Watson, J. D.

PUBLICATION INFORMATION: 1984, September

The Exceptional Parent, 14, 16-20.

This article discusses sexual abuse of children with disabilities and outlines the following reasons why these children are more vulnerable to sexual abuse than other children: (1) they are more likely to be dependent on adults for physical and emotional care, (2) they are encouraged to be passive and compliant, (3) they lack information or experience about appropriate sexual behavior, (4) the reluctance of families and institutions to discuss sexual abuse. The author makes suggestions about how to prevent sexual abuse, and how to respond to actual or suspected abuse.

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Lawrence, KS 66045-0048
(913) 864-4295

Center for Residential & Community Services
207 Pattee Hall
150 Pillsbury Drive, SE
Minneapolis, MN 55455

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1920 Association Drive
Reston, VA 22091-1589

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Boston, MA 02116
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